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ENCOUNTERS FOR LEARNING AND PARTICIPATION IN BREAST CANCER CARE

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**Karolinska
Institutet**

Stockholm 2017

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Published by Karolinska Institutet.

Printed by E-print AB

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ISBN 978-91-7676-601-9

Encounters for learning and participation in breast cancer care

THESIS FOR DOCTORAL DEGREE (Ph.D.)

at Karolinska Institutet to be defended in lecture room Samuelssonsalen
Tomtebodavägen 6

Friday 31 March 2017 at 9 am

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It does not matter how slowly you go, as long as you do not stop
Confucius (551- 479 BC)

ABSTRACT

The overall aim of this thesis, is to increase the understanding of how women's well-being, learning and participation during their breast cancer trajectory, especially in the context of short hospital stays, can be supported. The studies were conducted during two periods, with two different foci: Project I (study I-III) evaluated women's well-being in a setting with short hospital stays, after breast cancer surgery and increased continuity care. Project II (study IV-V) explored the experience and perceptions of how women learn and participate during a breast cancer trajectory in a day-surgery context.

In Project I (study I-III), patients were treated according to one of three care models: *Established care*, *Early hospital discharge* with drain in place and access to contact nurse, and *Continuity care* at a breast clinic with reduced hospital stay. The patients' perceptions of the disease, treatment and care and their Sense of Coherence (SOC) were evaluated with questionnaires. Patients with a reduced hospital stay were compared to patients treated in the Established care model. The hospital stay was reduced from six to two-three days. The length of the hospital stay was well accepted by the patients and did not have any effect on the patients' self-rated well-being. The patients' well-being and SOC before surgery was a predictor of their well-being after surgery. Those who preferred a shorter hospital stay were younger, had received less extensive surgery, were more often cohabitants and rated a stronger SOC. The staff continuity was appreciated and increased the possibility to meet the needs of the patients.

In Project II (study IV-V), women's experiences of learning, understanding and participation were explored in individual interviews. Three themes illustrate learning. *Interacting with a diversity of information* illustrates the vast amount of information the women interact with. Bodily sensations and experiences from being part of events are important sources. *Concealed and expressed understanding* describes how women interpret information and conceal or express their understanding. *Struggling to understand and manage the new life situation* reveals an ongoing struggle of grasping and processing the information, in order to understand and manage the many different situations they confront in daily life and during treatment and care. The preunderstanding and driving forces of the women, time for contemplation and dialogue with staff, were also essential features in this struggle. The women's understanding affected their participation in the care.

Three main themes illustrate how women perceive their participation. *Respectful and personal encounters* concerns how a respectful treatment from health care staff contributes to a feeling of being "seen" as a human and support participation. *Part-owner in decision making* focuses on the women's varied will and needs to participate in treatment decisions. *Striving to manage treatment, care and self-care* concerns the need to manage self-care for well-being in daily life and during treatment and care at the hospital.

Patients must be recognized as unique human beings, with varying needs of participation and learning, related to their understanding. A new approach is suggested, including patients as partners, and the health care staff as participants, in care and treatment. Dialogue with health care staff is a central prerequisite for the understanding and participation of patients, especially in the context of short hospital stays. This calls for a new kind of training programs, focusing on patient learning, for staffs and patients.

SAMMANFATTNING

Denna avhandling syftar till att öka förståelsen för hur kvinnors välbefinnande, lärande och delaktighet kan stödjas, under en bröstcancerbehandling med korta vårdtider. Studierna, som ligger till grund för arbetet, gjordes under två perioder med två olika foci. Projekt 1 (Studie I-III) utvärderade kvinnors välbefinnande, efter bröstcancerkirurgi med kort vårdtid och ökad kontinuitet i vården. Projekt 2 (Studie IV-V) utforskade hur kvinnor erfor och upplevde sitt lärande och deltagande under en bröstcancerbehandling med kort vårdtid – i huvudsak dagkirurgi.

I Projekt I behandlades patienterna i enlighet med en av tre vårdmodeller: *Den vanliga vården*, *Tidig utskrivning med dränage* och *kontaktsjuksköterska och Vård med ökad kontinuitet* på en bröstklínik och förkortad vårdtid. Patienternas upplevelser av sjukdomen, behandlingen, vården och Känsla av Sammanhang KASAM, utvärderades med hjälp av enkäter. Patienter med förkortad vårdtid jämfördes med patienter, som behandlats i den vanliga vården – med gängse vårdtider. Vårdtiden reducerades från sex till två – tre dagar. Vårdtidens längd accepterades väl av patienterna och hade ingen effekt på deras självskattade välbefinnande. Patienternas välbefinnande och KASAM före operationen visade sig dock vara en prediktor för deras välbefinnande efter operationen. De som föredrog en kortare vårdtid var yngre, hade varit föremål för mindre kirurgiska ingrepp, var oftare sammanboende och hade en högre KASAM. Patienterna uppskattade personalkontinuiteten och den därmed ökade möjligheten att få sina behov tillgodosedda.

I Projekt 2 utforskades kvinnornas erfarenheter av lärande, förståelse och delaktighet med hjälp av individuella intervjuer. Tre temata illustrerade lärandet. *Samspel med en mångfald av information* beskriver den omfattande mängd information, som kvinnorna hanterar. Kroppsupplevelser och erfarenheter av att vara en del av olika händelser var viktiga källor för lärandet. *Dold och uttalad förståelse* beskriver hur kvinnorna tolkar information och döljer eller uttalar sin förståelse. *Strävan efter att förstå och att hantera den nya situationen* visar på en pågående ansträngning att begripa och hantera information. Inte minst för att förstå och hantera de många nya situationerna, som kvinnorna möter i det dagliga livet och i vården. Kvinnornas förförståelse, drivkrafter, tid för kontemplation och dialog med hälso- och sjukvårdspersonalen var också viktiga i denna strävan. Kvinnornas förståelse spelade stor roll för deras delaktighet i vården.

Tre huvudtemata illustrerade hur kvinnorna upplevde sin delaktighet i vården. *Respektfulla och personliga möten* beskriver hur ett respektfullt bemötande från personalens sida bidrog till en känsla av att vara ”sedd”, som en människa och att detta utgjorde ett stöd för deltagande i vården. *Delägare i beslutsfattandet* fokuserar på kvinnornas olika vilja och behov av att delta i behandlingsbeslut. *Strävan efter att hantera behandling, vård och egenvård* berör behovet av att hantera sin egenvård för att öka välbefinnandet i det dagliga livet och under vård och behandling på sjukhuset

Patienter måste respekteras som unika mänskliga varelser, med olika behov av delaktighet och lärande i relation till deras förståelse. Ett nytt angreppssätt, som inkluderar patienter, som ”partners” och personalen, som deltagare i vården föreslås. Dialogen med personalen inom hälso- och sjukvården är ett centralt villkor för att patienterna skall kunna förstå och delta i den egna vården. Detta kräver att nya träningsprogram med fokus på patienters lärande, för såväl personal som patienter skapas.

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- IV. **Engqvist Boman, L.**, Sandelin, K., Wengström, Y., Silén, C. Patients' learning and understanding during their breast cancer trajectory. *Patient Education and Counseling*. 2016, <http://dx.doi.org/10.1016/j.pec.2016.12.024>
- V. **Engqvist Boman, L.**, Sandelin, K., Wengström, Y., Silén, C. Patient participation in breast cancer care-recognition of the individual woman. Manuscript.

CONTENTS

1	Introduction	1
1.1	Outline of the thesis.....	2
2	Background.....	3
2.1	Patients' experiences of breast cancer	3
2.2	Incidence and prognosis of cancer	3
2.3	Breast cancer treatment	4
2.4	Future challenges in health care	4
2.5	Project I – Patients' well-being	5
2.5.1	Psychosocial aspects and coping with breast cancer.....	5
2.5.2	The concept of Sense of Coherence	5
2.5.3	Short hospital stay	5
2.5.4	Caring encounters and well-being	6
2.6	Project II – Patients' learning and participation	7
2.6.1	Learning and education	7
2.6.2	Patient information	7
2.6.3	Patient education	8
2.6.4	Patient learning	9
2.6.5	Theories of learning	11
2.6.6	Patient participation	14
3	Aim	16
4	Methodology.....	17
4.1	Research approach.....	17
4.2	Research design and Methods.....	18
4.2.1	Project I - Patients' well-being (study I-III)	19
4.2.2	Project II – Patients' learning and participation (study IV-V).....	24
4.2.3	Ethical approval and considerations	30
5	Findings	32
5.1	Project I – Patients' well-being (study I-III).....	32
5.1.1	Effects of voluntary early discharge from hospital (study I)	32
5.1.2	Effects of continuity care, short hospital stay and SOC (study II)	32
5.1.3	Needs of care in a setting of short hospital stay (study III)	33
5.1.4	Summary of findings from Project I.....	34
5.2	Project II – Patients' learning and participation (study IV-V).....	35
5.2.1	Patients' learning and understanding (study IV).....	35
5.2.2	Patient participation in breast cancer care (study V).....	39
6	Discussion.....	42
6.1	Changes in breast cancer care and patients' well-being.....	42
6.2	Patients' learning, understanding and participation	43
6.3	Patients' learning related to theories of learning	44
6.3.1	Drivers for learning	44
6.3.2	Meaningful and transformative learning	45

6.3.3	Learning through variation	46
6.3.4	Learning through the lived body.....	47
6.4	Encounters for learning and participation.....	47
6.5	Methodological considerations	51
6.5.1	Project I –Patients’ well-being (study I-III)	51
6.5.2	Project II –Patients’ learning and participation (study IV-V).....	52
7	Conclusion	54
7.1	Implications for future practice	55
7.2	Future research	55
8	Acknowledgements	56
9	References	59

LIST OF ABBREVIATIONS

ICC	I Can Cope
KASAM	Känsla av Sammanhang
LND	Lymph node dissection
SDM	Shared decision making
SN	Sentinel Node
SOC	Sense of Coherence
VAS	Visual Analogue Scale

1 INTRODUCTION

Being diagnosed with a breast cancer is an overwhelming and frightening experience in many dimensions. A host of difficult questions, demanding prompt answers, immediately appear from nowhere. Questions about complicated medical issues are mixed with dramatic existential and psychosocial challenges. Answers are difficult to understand. There is a shortage of time. Treatment starts within a week.

The possibilities to treat and cure cancer have advanced significantly during the last decades with increased survival rates, shorter hospital stays and patients getting back to a “normal” life. This is also true for breast cancer. Albeit, there is limited knowledge about patients’ possibilities to participate and influence their situation during the course of the disease, and in what way efforts to support this could be introduced in clinical practice. This thesis entails a longitudinal approach to the development of breast cancer care and treatment in Sweden. The first part evaluates the introduction of short hospital stays in the 1990ies. The second part explores women’s understanding and participation in the current breast cancer care.

Project I describes women’s perceptions of their disease, treatment and care in the context of short hospital stays and high staff continuity, after breast cancer surgery. The project was motivated by the introduction of a mammography screening program and the following increased number of patients, in need of surgery.

Project II explores women’s learning, understanding and participation in treatment and care during their breast cancer trajectory. The second project was motivated by the need for increased patient participation in treatment and care, globally as well as in Sweden.

I have been involved since the first project started 1989 and was the first contact nurse for women with breast cancer at the department of surgery at the Karolinska Hospital. My training and experiences of supervising and teaching patients, relatives, students, health care staff, supervisors and teachers made me curious about patients’ learning. The increasing demands on health care to support patients’ understanding and participation, and recently published studies about patients’ dissatisfaction with information and participation led to my inquiry in this thesis.

1.1 OUTLINE OF THE THESIS

The projects in this thesis were conducted during two different periods of time with two main foci Project I: Patient's well-being and Project II: Patients' learning and participation. The theoretical background, methods and findings are presented related to the projects. In the discussion the two projects are integrated. An overview of the projects and studies in the thesis are presented in Table I. A brief introduction to the field of breast cancer is given in the first part of chapter 2.

Table I. Overview of the foci of the projects and related studies in the thesis.

Project I – Patients' well-being	
Study I	Effects of early discharge from hospital
Study II	Evaluation of two models of care and Sense of Coherence (SOC)
Study III	Needs of breast cancer care
Project II – Patients' learning and participation	
Study IV	Learning and understanding
Study V	Participation and understanding

2 BACKGROUND

2.1 PATIENTS' EXPERIENCES OF BREAST CANCER

An early Swedish study revealed that women needed psychological support a long time after breast cancer treatment (1). There was a need for increased information and opportunities for the patients to discuss with the staff. Women also needed time to prepare themselves psychologically before treatment and to process their experiences. Loma Feigenberg (2) highlighted the complexity of being diagnosed with cancer as it concerns a person's life and death. He states that patients' understanding of cancer – the subjective concept of cancer – differs from that of the doctor – the objective concept of cancer. It takes more than objective facts and knowledge, to handle and alter attitudes to cancer. Carefully designed information and education to patients, empathic treatment by the staff and the need for continuity and consistency of the care were emphasized (2).

Twenty years later similar desires were reported among patients diagnosed with breast cancer, expressing a need of easy access to health care, competence and continuity in the treatment, adapted continuous information and respectful and honest treatment (3). When these needs were met, the patients felt they were a part of “A helping plan”. Kok et al (4) developed an instrument to measure quality of care in collaboration with patients treated for breast cancer. The wish to be treated as an individual person, and not merely as a number, was a core theme. The most important parts of breast cancer care, mentioned by the patients, were education, involvement in decision making, skills of the care givers, continuity of care, psychological aspects and waiting time. A recent review showed that women diagnosed with breast cancer perceive a considerable number of unmet needs of supportive care, most frequently with regard to information and psychological support (5).

Breast cancer has been described as a transforming experience contributing to both positive and negative changes (6-12). Breast cancer survivors have reported physiological and emotional needs, as long as five years after diagnosis, and support from health care is required to understand and cope with the situation (13). The most frequent body symptoms recently reported one year after breast cancer treatment are sweating, sleep problems, inconvenience from the joints, pain and mouth dryness (14). The body image is affected by the breast cancer treatment, but not necessarily to sexual disturbances, which rather were related to having a steady partner and low education (15). The need to provide the women with information about the impact of the disease and treatment on life and sexuality was pointed out. Health related quality of life has been shown to be a prognostic factor in breast cancer treatment and outcomes of the disease (16).

2.2 INCIDENCE AND PROGNOSIS OF CANCER

Cancer is a major cause of morbidity worldwide, with 14 million new cases and eight million deaths recorded in 2012 (17). It is calculated that twice as many people will live with cancer in Sweden in 2040 compared with 2013 (18). The estimated survival rate of five years for all

cancers is about 70%. The most common forms of cancer in Sweden are prostate and breast cancer, followed by skin, colon and lung cancer. Breast cancer is the most common form of cancer among women worldwide (17). In Sweden 8 270, new cases (7 963 women and 59 men) were reported 2015 representing about 30 % of all female cancer (19). The incidence has increased in average 1,4 % since 1970 but during the same period the mortality rate has remained constant. The relative five years survival rate today is 91% for those having invasive breast cancer without distant metastases (20). The relative 10 years survival rate has increased from 50% in the 1960's to 80% in 2011. The reasons for increased survivors are earlier detection, smaller tumor sizes due to the mammography screening and improved medical adjuvant treatments.

2.3 BREAST CANCER TREATMENT

Management of breast cancer combines surgical tumor removal with chemo-, immune- and radiation therapy. Surgical options are breast conservation and total mastectomy with the addition of axillary procedures. In Sweden, the less invasive sentinel node procedure, i.e. removal of one axillary lymph node dominates. The more extensive approach of lymph node dissection, i.e. removal of several axillary lymph nodes, is used for patients with axillary metastases.

Radiation therapy is the standard treatment after breast conserving surgery and sometimes it is also used after mastectomy as it reduces the risk for relapse and death of breast cancer (21). The majority of breast cancers of Swedish patients are sensitive to estrogen which stimulates growth of the cancer cells. These patients are recommended anti estrogen treatment. This treatment substantially reduces both relapse of the cancer and improves survival. However, as the side effects can be serious with hot flushes, night sweats, vaginal dryness, weight gain, many women stop taking the drug (20).

2.4 FUTURE CHALLENGES IN HEALTH CARE

Since project I, breast cancer treatment and care in Sweden have undergone major changes. The hospital stay after the surgical treatment has been reduced, from about six days in the 1990ies to 24 hours or less today. A yearly national follow-up of quality indicators in breast cancer care is performed by the National Breast Cancer Registry (20). Patient reported outcomes of treatment and care, the access to a contact nurse and the individual care plan are included as quality indicators. Due to the mammography screening, tumors are detected earlier and are smaller, and a less extensive surgery in the axilla and breast is needed. The number of survivors have increased due to early detection and improved treatment, and there is an increased knowledge about prevention. What these changes mean for women's learning, understanding and participation in managing their well-being during their breast cancer experience need to be followed-up and motivate Project II.

2.5 PROJECT I – PATIENTS' WELL-BEING

2.5.1 Psychosocial aspects and coping with breast cancer

Between the late 1970's and 1990's the psychological and psychosocial consequences of having breast cancer were extensively studied. Emotional distress such as stress, anxiety, depression and disturbances in body image and sexual function were reported (1, 22-27). The women who had a mastectomy or lymphedema experienced a disruption in their quality of life (23, 28). Social support was related to better adjustment to the new situation but the personality and the coping behavior were considered to be most predictable in the adjustment (27). Most women recovered during the first year and for some the breast cancer experience contributed to a changed view on life (29-31). Coping strategies which promoted good psychosocial adaptation were related to maintained self-control, searching for information and support (32, 33). Catastrophizing, resignation, passive avoidance and blaming oneself or others were related to poor adjustment (32, 34, 35).

2.5.2 The concept of Sense of Coherence

The ability to cope with stressful events has been suggested to be related to the individual's Sense of Coherence (SOC) (36). The concept was created by Antonovsky and represents an individual's view on life in general including cognitive, emotional and instrumental dimensions. Three components are involved in SOC: Comprehensibility, Manageability and Meaningfulness which are interrelated. Comprehensibility reflects an individual's perceptions of how understandable, predictable, ordered and explicable future and present life events are. Manageability concerns the individual's perceptions of having adequate resources to cope with the straining events. Meaningfulness is related to an individual's commitment and sense making of life events (36). At time for project I, several studies had shown that the stronger patients rated their SOC, the better were their self-rated well-being and functional status (37-43). The SOC scale was therefore included in project I, study II to increase the understanding of its relation to the women's well-being during breast cancer treatment and care.

2.5.3 Short hospital stay

At time for project I, short hospital stays after breast cancer surgery had been introduced and evaluated mostly in USA. In 1989 a mammography screening program (44) was introduced in Stockholm and an increased need for breast surgery was expected. As a consequence the length of the hospital stay was reduced for the patients in combination with an increased continuity with the health care staff in connection with breast cancer surgery. Studies about short hospital stays after breast cancer surgery focused mainly on financial and medical evaluations (45-49). The results showed reduced health care costs, safe care and high acceptance among patients. In one study patients were discharged within 23 hours after surgery. Most patients, who had their drain in place had no difficulties to handle it and felt prepared to leave the hospital (50). The patients appreciated the education and care provided by surgeons and nurses. However, 21% desired a longer hospital stay as they needed to learn more about self-care.

Most of the evaluations about the patients' perceptions of short hospital stays lacked information about the methods used and mostly described overall patient satisfaction. Patients' well-being, needs of learning and understanding of their disease and treatment were not reported.

2.5.4 Caring encounters and well-being

Patients' experiences of nursing care have been described as promoting well-being through the nurse's willingness to relate, which generated feelings of comfort and trust helping patients through the transition (51). This is in accordance with cancer patients' descriptions of caring encounters, when the nurse is perceived as a caring companion contributing to trust, empowerment, well-being and healing. (52). Others have described patients' experiences of good caring as including both the relational aspects as being treated with respect and trust, and task oriented as being adequately assessed and treated (53). Further, Dunkel-Schetter (54) identified four types of support, given by health care providers, being emotional, informational, appraisal and instrumental. The emotional support was considered to be the most helpful. These findings are in line with others who found that the emotional support related to patients' enhanced feelings of safety, security, adjustment and satisfaction with the treatment (27, 55-57). Information about the disease, treatment, test results and recurrence has also been shown to help patients and their spouses to cope with the breast cancer experience (58-61). Younger patients and those receiving chemotherapy are reported to need more information and support (62, 63).

Breast cancer patients and nurses were found to hold different views about which kind of support patients needed. Patients thought they received insufficient professional support and information while most nurses saw themselves as supportive enough (61, 64). Poor communication with health care staff was considered to cause psychosocial problems among patients diagnosed with cancer because they were not detected or adequately assessed by the staff (65-68). Continuity, limited number of care givers, interaction and communication with surgeons and nurses seem to be related to the possibility of a correct assessment of the patients' situation, needs of and satisfaction with the care (25, 53, 69-74).

At time for project I, there was a need for an increased understanding of the influence of a reduced hospital stay, combined with increased care continuity, on the well-being of patients. In Project I, well-being includes the emotional perceptions of the patients, their information-seeking behavior, available social support and satisfaction with treatment and care of their breast cancer.

2.6 PROJECT II – PATIENTS’ LEARNING AND PARTICIPATION

According to the new patient legislation, healthcare staff in Sweden is obliged, not only to assess and meet patients’ need for information, but also to follow up their understanding and participation (75). This expectation is challenging for healthcare organizations and there is a need to investigate how patients can be supported to participate in care and treatment. Participation requires patients’ understanding. Project II aimed at exploring women’s learning, understanding and participation during their breast cancer trajectory.

2.6.1 Learning and education

Learning includes both a content – what is to be learned– and a process – how the learning proceeds. The what-aspect of learning, i.e. the patients’ needs of information has been well studied since three decades and is not in focus of study IV. However, as the what-aspect is an important part of learning, a summary of selected research about patients’ needs, sources and approaches to information is presented below.

2.6.2 Patient information

Women with breast cancer have broad needs of information and positive associations have been found between high satisfaction with information and health related quality of life (76-78). Needs of information concerning the disease, treatment and diagnostic tests got the highest rank among women with breast cancer (62). Information about how to manage the disease was rated higher than psychosocial concerns. Younger women rated their need for information higher than older. The needs varied during the disease. O’Leary et al (79) reported similar findings and that a majority of the patients with breast cancer wanted as much information as possible. Physicians were the preferred source of information followed by other health care professionals. Family, friends, books, brochures, pamphlets and the Internet were also frequently used sources. Humans were preferred as sources of information, because it made clarifying interaction possible. Since many years, the need for improving information and communication has been emphasized to achieve good cancer care (78, 80-84). However, information is still one of the most unmet supportive care needs among women in breast cancer care (5).

Patients’ needs for information during cancer treatment are well studied during the last decades as demonstrated in extensive reviews (85, 86). The most frequent needs of information were similar to those found in breast cancer care, i.e. it concerned disease specific questions and treatment. One of the reviews (85) showed that patients still need information about the treatment and recovery after treatment. Information increased patient involvement, in and satisfaction with, decision-making about treatment options. Information also improved the patients’ communication and coping ability and quality of life. Kav et al. (87) found that cancer patients in Turkey first wanted information from the physician about the diagnosis and treatment, and thereafter from internet, media and nurses. Younger patients, with higher education, sought information more actively. The beliefs and coping strategies of the patients could limit their desire and search for information.

Hautamäki et al (88) found that patients who perceived negative effects on their sexuality and relationships, due to their cancer had a great need of information about sexual issues.

Tariman et al. (86) also showed that younger patients prioritized information about sexuality higher than older patients who prioritized information about self-care higher than younger patients.

Leydon et al. (89) interviewed 17 patients with cancer about information avoidance. Three main attitudes - faith, hope and charity- were identified as obstacles for information seeking. Faith in the physician's medical expertise reduced the need of patients to seek other sources of information. Hope could be maintained if information was avoided. Charity to fellow patients meant that patients accepted limited information because they didn't want to take scarce resources from other patients. The authors conclude that the strategy of cancer information must pay attention to the patients' varied needs of information.

Lithner (83) found that patients, treated for colorectal cancer, desired more information to be able to control their lives, facilitate the transition from the hospital to home, to understand what the disease meant to them and to manage their worries. Lacking information caused anxiety and insecurity. It was concluded that patients should be offered multiple ways of accessing information after discharge from hospital.

The content of patient learning, i.e. the information needed during breast cancer and other cancer diagnoses show similarities. The information concerns all aspects of the cancer disease and treatment and coping with the situation. The needs vary between patients and during the course of the disease. The patients' avoidance, to take up too much time of the staff for the sake of other patients, needs to be acknowledged in clinical encounters. Even though many of the studies are aiming to generalize the findings, there is a consensus about the necessity of individual assessment of patients' needs of information (62, 79, 85-88). In addition the need for improving the information disclosure by developing the communication process has been emphasized (76, 90).

2.6.3 Patient education

Information is the content of learning. The need for patients to understand information and cope with the illness has been in focus in patient education. Below is a brief summary of previous efforts in patient education in cancer care.

Patient education has been an important part of nursing since the middle of the 19th century when Florence Nightingale taught patients how to improve their well-being (91). In USA patients' rights to education are regulated by health organizations and federal authorities and patient education is spread across the country (92). Literature about how to design patient education highlights the necessity of using theories of learning (93). The authors presented behaviorist, cognitive, social, psychodynamic and humanistic learning theories and how teaching and learning are approached in each of them. Studies about patient learning, however, were not presented.

An educational program for cancer survivors and their families, the “I Can Cope” (ICC) program, was started 1979 by the American Cancer Society and has been highly appreciated by the participants (94). Inspired by the ICC program Granh (95) developed a Swedish education and support program, “Learning to live with cancer”. It was based on the learning needs of cancer patients and their relatives and concerned the disease, treatment and the adaption process. The author argued for the need to change focus from informing to supporting learning and understanding. She refers to the pedagogic learning models by Piaget, Dewey and Montessori and point out the need for viewing teaching and learning as a dynamic and interactive process. The need for reflection and reasoning is also emphasized. The aim of the program was to transform the experience of suffering from cancer to a meaningful experience of living with cancer. The evaluation showed that the program supported the understanding and coping ability of the participants, but only half of the eligible patients participated (96). The evaluation was not explored related to the pedagogical models which could have been interesting in explaining the findings further.

A similar cancer rehabilitation program called ”Starting again” was developed at the same time as “Learning to live with cancer”, in Sweden. This program concerned physical and coping skills, training and information. The results of an evaluation showed that those who participated in the program rated higher improvement in all areas, compared with a control group (97).

Norway has legislated that users/patients must be involved in all aspects of their health care. Patient education is one of the four main missions for health care in Norway and today there are 60 “Learning and Mastery Centers” which offer courses in co-operation with users/patients. However, patients’ participation has been questioned, since they did not have any real influence on planning, implementation or evaluation of the courses (98).

In summary, patient education has a long history with the purpose to improve health, wellbeing and the ability to cope with a disease. The legislation has been an important factor in USA and Norway in the implementation. Considering the increasing demands on patients to take care of themselves and participate in health care, patient education can be considered as a part of health care. Research about patients’ education and learning during cancer treatment has mainly focused on knowledge and emotions (99-103). As not all patients want to, or can, attend a course it is important to increase the knowledge about how all patients can be supported to learn and participate in the health care.

2.6.4 Patient learning

The learning of the individual patient is not a very well-studied area, but can offer new perspectives and insights on how patients develop understanding during the course of their illness. Previous studies about patients’ learning about breast cancer have focused on self-directed learning and the use of computer based systems (104-106). An interview study with 13 women, who had used self-directed learning, i.e. searched for information and support on their own, showed that this was an important part in their coping with their illness (104). The

drivers for self-directed learning of the women were fear, and a need to understand how to help one self and to be able to participate and understand treatment decisions. The women started to search for information after diagnosis, when they had recovered from the initial shock. The amount of time spent looking for information was at least 7 hours. They used printed material, the Internet, family, friends and support groups and reported difficulties to find and evaluate resources. Coping with emotions was a barrier for absorbing and understanding the huge amount of information. Sometimes, support groups were barriers for coping, because of the mix of women in different stages of the disease. Five learning outcomes were identified among the women: increased self-confidence, a desire to use what was learned to help other breast cancer patients, increased confidence in treatment decisions, reduction of the emotional stress and fear associated with breast cancer and increased knowledge. The self-directed learning helped patients to meet emotional and psychosocial needs which were not met in health care. Self-directed learning was difficult but beneficial (104).

The knowledge about patient learning, in other fields of health care, might be applicable to breast cancer as well. Recent studies are presented in the context of diabetes, heart, and chronic diseases and in physiotherapy (107-110).

Berglund (107) described the learning experience of living with a long term-illness as a complex ongoing process, which includes the whole life-situation of the individual, and not only the illness. Learning supported changes in life and an increased understanding of one-self and others and of taking charge of one's life.

The experience of learning to live with diabetes was subject to a three year follow up study with 13 newly diagnosed persons (109). Close to the diagnosis, the participants' knowledge emanated from their experience and reflections. The process of learning was characterized by an inner dialogue between the self, body and life (111). Three years later the findings showed that the body was crucial in the learning process, and the experiences fluctuated between balance in life and a daily struggle, and between objectifying a disease and integrated and illness (112). The participants' understanding of their illness and self-management changed gradually and an increased awareness of body signals, seeking information and reflecting were essential parts of the learning process (113). Johansson et al (108) confirmed the need for reflection in supporting patients' learning to live with diabetes and added that patient's awareness of their own responsibility was a key factor.

Learning has also been studied by using conversation analysis of physiotherapy sessions, showing how a patient's learning was constructed through verbal and non-verbal longitudinal interaction with the physiotherapist (110).

It is not clear how online interventions can be beneficial for cancer patients (106, 114).

Ventura et al (106) concluded that their computer based educational program might not have been relevant or useful for the participants with breast cancer as the information was delivered one-way. To use a constructivist approach to learning, i.e. to organize the computer

based services to permit interaction with others was shown to support the learning of women with breast cancer (105).

2.6.5 Theories of learning

Learning theories are assumed to contribute to a deeper understanding of how women with breast cancer interpret and understand information. This project rests on a constructivist paradigm, in which the learner is viewed as an active participant in processing information to construct his/her understanding individually and in interaction with others and the environment (115, 116). Learning includes both the process of how something is learned and what is learned, i.e. the learning outcome (117). Learning is a multifaceted and complex phenomenon which cannot be explained by one single theory. Special circumstances for learning can be expected during a serious illness, as the patient faces an uncertain future with dramatic existential implications. The term andragogy was introduced by Knowles (118) not as an empirical theory, but as a description of the adult learner, which can be applied to women with breast cancer. The basic beliefs, within andragogy are in line with the constructivist approach. This means that learning requires the learner to process information cognitively, emotionally, and through practice, individually, and in interaction with others, to create understanding. Knowles presented five assumptions; Adults are self-directed learners, Adults' experience is a resource for learning, Adults value learning that helps them in their social role, Adults value learning that can be immediately applied to authentic problems and Adults learn more by internal motivation than external. The theories below are selected to explore the phenomena of adult learning during breast cancer, in accordance with the constructivist view on learning.

2.6.5.1 A comprehensive theory of learning

Illeris (119) claims that there is a need for a comprehensive understanding of learning based on theories from psychology, biology and social science developed during the twentieth century. All learning involves two processes which have been studied separately. The internal psychological processes within the learner are focused in the behaviorist and cognitive learning theories. The external interaction between the learner and the environment are focused in social learning theories. Illeris has merged the learning theories into a comprehensive model. It illustrates an integrated interplay between three dimensions of learning which are the (1) interaction between the environment and the individual, (2) the individual's manageability and incentives for acquisition of the (3) content. The content is what is learned from various sources of information. In the acquisition of the information the learner constructs meaning and ability to develop functionalities to deal with new challenges in life. The dimension of incentives includes drivers such as emotions, motivation and will to learn, aiming for mental balance of the learner. Learning always involves body and mind, including the cognitive and emotional areas of the brain. The concept of learning in this model is based on constructivism, meaning that the learner actively construct mental structures in the brain and new stimuli is connected to previous structures, i. e. the new understanding is related to previous understanding (119).

2.6.5.2 *Transformative and Meaningful learning*

The transformative learning theory is in line with the comprehensive learning theory presented above inasmuch that understanding is constructed by the individual in interaction with others and the context. Mezirow (120) introduced the concept of transformative learning 1978 and the theory was developed through his study on women's adult education in USA, using Grounded Theory methodology. Since then the transformative learning theory has been widely spread in North America and developed in adult education as well as in health and social welfare. According to Mezirow (120), we construct meaning from our experiences through our frames of reference. It affects our perceptions, cognition and feelings which constitutes our preconceptions of the world. He argues that the frames of reference, including both our habits of mind and our expressed points of view, form our interpretations. The process of transformed learning includes critical reflection on one's own and others' assumptions, assessing truth and changing beliefs and actions. The two main elements of transformed learning are critical reflection and participating, in a dialectic discourse, to validate a best reflective judgement. Moreover, a life crisis, like being diagnosed with breast cancer, may contribute to a sudden reorientation of habits of minds - called epochal, in contrast to a cumulative process. The epochal reorientation is guided by intuition and not by critical reflection, and most of the transformed learning happens outside awareness. Mezirow highlights the educator's role in facilitating the transformative process. In addition, he presents universal dimensions of adult understanding. These are to seek and make meaning of experience through one's frames of reference, sensing one's own capability to act and engage in learning. Adult understanding is also characterized by an acceptance and reliance of alternative interpretations and understandings and to engage in reflective discourse to assess reasons, assumptions and alternatives. Critical reflection is an important dimension of adult understanding in transforming one's frames of reference (120).

Mayer (121) takes his point of departure in the cognitive processes within the learner. He argues against the commonsense view on learning being to gain knowledge. This affects the teachers to present information and to test the learner's ability to remember. Instead the teachers should support a meaningful learning in which the learner is able to make sense of the content of the learning and use it. To be able to create an understanding the learner needs to use cognitive processes of interpreting, exemplifying, classifying, summarizing, inferring, comparing and explaining.

Marton and Booth (117) present the extensive research done by a group of researchers during 25 years aiming at understanding why students succeed differently in learning. The short answer is that they found that students' approaches to learning differ between reproducing knowledge and seeking meaning of what is learned, and that the awareness of the individual affects the understanding of a situation. A situation, e.g being diagnosed with breast cancer, is always interpreted from previous experiences related to the phenomenon, i.e the disease breast cancer which gives meaning to the situation. The understanding of a phenomenon is modified when experienced in the new situation. Therefore the learning differ between and within individuals depending on the understanding of a phenomenon and the current situation

- the context of learning, the task - what is learned, and the act - how it is learned. Furthermore, the how aspect can be divided into how the act is performed and what capabilities the learner develops in acting, i. e. an indirect object of learning.

2.6.5.3 Learning through variation

Marton and Booth (117) claim that learning occurs when an individual becomes aware of something. This something needs to be discerned in parts, which must be related to one another and the context. The awareness is focused on some parts, which come to the fore, while other things stay in the background of the mind. This means, that when a person perceive something different compared to previous experiences, this something is discerned and come to the fore of the individual's awareness. Discernment is at the core of experiencing a phenomenon. Without variation there will be no discernment and no learning (122). For instance, if you never have experienced light you cannot experience darkness.

2.6.5.4 The lived body

The lived body is the phenomenon of being in the world and our experiences of being here are incarnated (123). Bodily experiences are important aspects of the learning process and can be understood in the context of phenomenology. In his work *Phenomenology of Perception* (124), Merleau Ponty argues against the Cartesian view of the body as being an object divided from the soul. Instead he claims, that the body and soul is one entity and that consciousness is shaped through the body. The body is not an object possible to understand by dividing it in parts as the parts are involved in each other in an unclear and implicit way. Therefore there is no other way of gaining knowledge about the body than through perceiving it. In addition, learning about the world means to perceive and process a variety of stimuli through the body and internalize the new understanding as part of the individual (124).

Leder (123) builds on the ideas of Merleau Ponty, when he introduces the "Absent body", which is the state when the body is un-noticed or is in the background of the mind. The aim of the work by Leder is to increase our self-understanding, by exploring the phenomenon of the absent body. Leder describes three modes of body absence concerning the surface body, the inner body, and the presence-absence which is correlated to the previous. He argues, that even if we perceive the world through our eyes, ears, hands and communicate with the world through our expressions in the face, speech and feelings, the body itself is not the object of experience. In that sense the surface of the body is absent from our consciousness. The depth of the body, as the visceral organs, are concealed for our apprehension and control and therefore absent from our awareness. When the body is functioning it is not noticed and in that sense disappeared from our consciousness. The third mode is intertwined between presence-absence states, where the body appears to our mind when it is dys-functioning, named dys-appeared. Leder discusses pain, disease and social breakdown as examples of when the body dys-appears but is absent from a desired state. He suggests the lived body as an alternative to the Cartesian view of body and mind as divided parts. That is because he consider the latter has influenced the encounters between patients and health care staff when

patients experience themselves treated as a “thing”. Instead he argues for uncovering phenomena that are concealed, and pay more attention to the patient’s experience and subjective voice to promote their healing (123).

2.6.6 Patient participation

Patient participation is considered to be an essential part in clinical encounters in the 21st century, as part of the paradigm shift to patient-centered care to improve patient safety and well-being (125-129). There are however, several obstacles to patient participation. One is that it is not clear what the concept means, as it has been used interchangeable with other concepts, such as patient centeredness, empowerment and involvement in health care (130). The attitudes to patient participation and lack of knowledge among health care staff and patients complicate matters further (131, 132). Patients and staff have demonstrated different views on what, and to which degree patients want to participate in their care, and there is confusion about roles and expectations (129, 133-135). As patient participation is complex it needs to be explored from the patients’ perspective in order to facilitate communication with health care staff (131, 136, 137). Patients have been reported to focus more on having knowledge than on being informed, and on interacting with health care professionals rather than on taking part in decision making when defining participation (138). To be able to participate in their own care patients need a trusting relationship with staff, knowledge and power in the clinical encounter (128, 139, 140).

Patients need support to understand available treatment options. Inadequate information has been found to be a significant barrier to shared decision making (SDM) about treatment (128). Patients treated for colorectal cancer, and their relatives, have reported that they had wished to participate more in the exchange of information with the health care staff in order to understand and manage their situation (83). In a study by Durif-Bruckert et al., (141) the quantitative and qualitative methods used showed contradictory results about patients’ perceptions of the SDM process about breast cancer surgery. The patients rated high satisfaction with the SDM process. At the same time 43% reported that they had not understood the information, at the time of the diagnosis, due to the emotional shock. They also expressed ambivalence to SDM. The difficulty for patients with breast cancer to choose between mastectomy or breast conserving surgery is confirmed in several studies, and the need for improving the communication skills of both health care staff and patients is emphasized (132, 142, 143). In addition, recent studies have illustrated the need for improved information to support women, also during their treatment for breast cancer (5, 76, 144).

Studies on the opinions of health care staff about patient participation have shown varying results. Légaré and Thompson-Leduc (145) found twelve myths held by health care staff about shared decision making being: “it’s a fad and will pass”, “patients are left alone”, “not everyone wants it”, “not everyone is good at it”, “it is not possible as patients ask the doctor what he/she would do”, “we are already doing it”, “it takes too much time”, “it is easy with a tool”, “it is not compatible with treatment guidelines”, “it is only about the doctors and their patients”, “it costs money and does not account for emotions”. Nurses have described

themselves as facilitators of patient participation by acknowledging the patients as partners, respecting their knowledge and choices, informing and encouraging them to be actively involved (146). The nurses sometimes perceived their tasks of managing risks and patient safety, legal parameters and the patients' abilities and preferences as barriers to participation of the patients.

Considering the complexity of patient participation, and the call for changing roles of patients and staff, it has been suggested that education should be provided to all included (131, 136). The role of the patients has moved from the paternalistic and the patient-centered approaches to the patient-as-partner approach, where the patient is considered to be a member of the team (137). To accomplish this approach the patients' perspectives on partnership need to be explored, as they are experts on the experience of their illness (137, 147). As pointed out, patients' knowledge and understanding are prerequisites for their participation (125, 131). The need for creating an educational environment and pedagogical encounters between patients and staff has long been emphasized (148, 149). This means to see the patient as a learning person, rather than as a passive recipient of information. Therefore we need to understand patients as learners. How do patients learn and become knowledgeable? How are learning and understanding related to participation? The questions motivate study IV and V.

3 AIM

The overall aim of this thesis, is to increase the understanding of how women's well-being, learning and participation can be supported, during their breast cancer trajectory, especially in the context of short hospital stays. The specific aims are:

Project I – Patients' well-being

Study I

To evaluate the effects of early discharge from hospital, after breast cancer surgery, with regard to women's state and perceptions of the disease, health, treatment and care.

Study II

To evaluate women's state and perceptions of their disease, health, treatment, and care related to Sense of Coherence and two different models of care.

Study III

To describe the expressed needs of women after surgical treatment for breast cancer in a setting of continuity care and short hospital stay.

Project II – Patients' learning and participation

Study IV

To explore how women learn about and understand their disease, treatment, care, and life-situation during their breast cancer trajectory.

Study V

To explore how women experience their participation in treatment and care of breast cancer related to their understanding of the situation.

4 METHODOLOGY

4.1 RESEARCH APPROACH

The common aim of the projects in this thesis is to increase our understanding of women's perceptions and experiences of having breast cancer. Depending on the research questions different approaches and methodologies have been used. In Project I the research question was how women's well-being was affected by a short hospital stay and high continuity care. That project was based mainly on comparisons between groups of patients treated in different care models. In Project II the research question was how women learn and participate in their breast cancer care, aiming to capture the variation of the phenomena.

A paradigm is defined as a framework of beliefs underlying the research. It includes ideas about the world (ontology), how it can be understood (epistemology) and studied (methodology) (150). Lincoln et al. (116) have described different paradigms being positivism, post-positivism, critical theory, constructivism and participatory paradigm. In positivism, the beliefs are that there is a "real" reality, which can be captured (ontology), the findings represent the truth (epistemology) mainly produced through hypothesis testing using quantitative methods (methodology). The post positivism paradigm share the same ontology as positivism, but the reality is assumed to be impossible to capture perfectly. Therefore the findings from experiments are quantitatively evaluated using statistics and considered probably true. Qualitative methods may be included. Constructivism on the contrary is based on relativism, i.e. there are multiple realities, which are studied using interpretive naturalistic (in the natural world) methodology and the findings are co-created by the researcher and the objects of study (subjectivist epistemology) (116, 150).

The research design of Project I (study I-III) relates to the basic beliefs of the post positivistic paradigm (116). The epistemological view is that objectivity is seen as the ideal and a critical community helps to keep the objectivity and findings are probably true (116). The sampling, data collection and analyses aim at producing results on a group level generalizable to a population as for instance breast cancer patients. Based on this paradigm the aim of study I-II was to compare data between groups and explain what factors are predictable for well-being. Study III aimed at evaluating the content and frequency of satisfied and unsatisfied needs of care based on an open ended question in a study specific questionnaire. The method of analysis was inspired by Grounded Theory, which was developed within a post-positivistic paradigm (150). However, the interpretation of the data is more related to a constructivist paradigm.

Project II (study IV-V) takes its point of the departure from the perspective of a constructivism paradigm as described by Lincoln et al. (116). The ontology in this paradigm is that reality is viewed as being relativistic, i. e. it is related to how individuals perceive and interpret it, constructing their own understanding of the reality. This means that the reality can be perceived and understood in different ways depending on the individual's experiences

and the social context. The epistemological view is that knowledge creation is transactional and subjectivist, which means that the results are created in the process of interaction between the investigator and the object of the investigated. The methodology is hermeneutical and dialectical, meaning that the researcher interprets the constructions presented by the objects of the investigation and compare and contrast them, through a dialectic interchange. Interview, as a method of data collection, aims at creating knowledge in relational and interactive conversations.

The performance of the interview is depending on the aim of the study and the link to different research philosophies. Kvale and Brinkman (151) present two metaphors, the interviewer as a prospector or as a traveler, related to two different epistemological ideas. The prospector is digging for ore, collecting the knowledge, in the interview and is looking for objective data or subjective authentic meanings. The interviewer is considered being neutral without any impact on the data. In contrast the aim of the interviewer approach as a traveler is to construct knowledge during the trip to a foreign country and tell about it after the return home.

4.2 RESEARCH DESIGN AND METHODS

An overview of the studies, the participants, the methods used for data collection and analyses are presented in Table II.

Table II. Overview of the study focus, participants, data collection and analysis in the thesis

	Study focus	Participants	Data collection	Data analysis
Project I				
Study I	Effects of early hospital discharge	118 women Group 1: 28 Group 2: 90	Study specific questionnaire Medical data	Factor analysis Descriptive and comparative
Study II	Evaluation of two care models and SOC	144 women Group 1: 29 Group 2: 115	Study specific questionnaire SOC scale	Factor analysis Regression analysis
Study III	Needs of care after surgery	97 women	Open ended question	Modified constant comparative
Project II				
Study IV	Learning and understanding	16 women	Individual Interviews	Content analysis Abductive analysis
Study V	Participation and understanding	16 women	Individual Interviews	Content analysis Abductive analysis

4.2.1 Project I - Patients' well-being (study I-III)

4.2.1.1 Research design and settings

Study I and II have a prospective, comparative design. Study III is descriptive. Data was collected by questionnaires and recordings of medical data. The participants in Study I were recruited from surgical departments in two hospitals in Stockholm, and in Study II and III from one of the hospitals. Patients with primary breast cancer, proficient Swedish speakers and in a mental and physical condition allowing participation, were included. Data collection in study I was performed January 1988 - October 1989 and in study II and III February 1989 - June 1990.

4.2.1.2 Participants

The participants in the three studies are presented in Figure 1.

In study I, a total of 118 patients were included. All participants answered a questionnaire, were offered a voluntary early discharge from hospital, with an axillary drain in place after surgery and access to a contact nurse. Twenty-eight (24%) participants (Group 1), choosing an early discharge with drain in place, were compared with 90 (76%) patients (Group 2), who remained in the hospital, until the drain was removed, without access to a contact nurse.

In study II a total of 144 patients participated in the study. The participants were treated in two different care models and discharged without drain. Group 1 (n=29) was treated in the "Established Care" model with several surgeons and nurses responsible for the care. Group 2 (n=115) was treated in a "Continuity Care" model by an interprofessional team at a breast clinic.

In study III, 132 patients cared for in the "Continuity Care" model, and discharged with and without a drain, answered a questionnaire. Ninety-seven of these answered an open ended question about their needs in connection to their treatment for breast cancer and were included in the study.

4.2.1.3 Different care models used in the studies

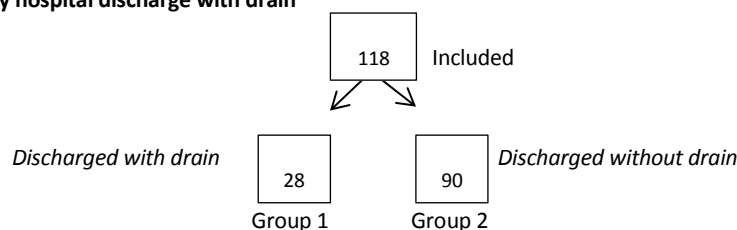
Study I

All patients were admitted to the surgical ward the day before surgery and the contact nurse (LB) informed about the study. All were given information about the option of an early discharge from hospital with an axillary drain in place. Two days postoperatively the contact nurse visited those who participated in the study and encouraged them to choose an early discharge. Those who accepted were given careful instructions about the procedures. The patients were instructed to empty and measure the drainage volume, each day, until it was less than 30 ml/24 hours, which was the time for removal of the drain. They were also told to contact the nurse whenever they needed and for removal of the drain.

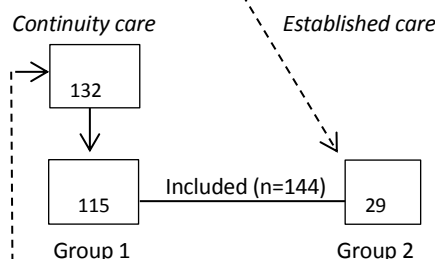
Study II and III

Two models of care were evaluated as part of a development program in breast cancer care. The model “Established Care” was used for patients treated in one of the hospitals in study I. The patients in Group 1 were admitted to the surgical ward the day before surgery, were discharged from hospital without drain, and had no access to a contact nurse. The patients in Group 2 were treated in the “Continuity Care” model. It included a reduced hospital stay and an increased continuity in patient contact with an interprofessional team at an out-patient breast clinic focusing on supply of information and psycho-social issues. The models of care are presented in Table I in paper II. The patients treated in the “Continuity Care” model, discharged with or without drain, were included in Study III and answered an open ended question about their needs of care.

Study I - Early hospital discharge with drain



Study II - Evaluation of two care models and SOC (discharged without drain)



Study III - Needs of care after surgery (discharged with and without drain)

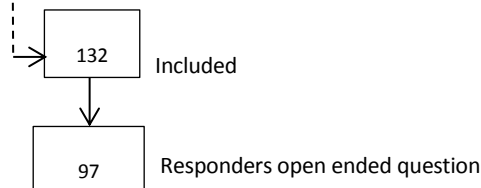


Figure 1. Participants in study I-III, numbers are given.

4.2.1.4 Data collection

Medical data

The stage of the disease, type of surgery, length of hospital stay, duration of drainage tube in place, volume of drainage fluid and postoperative complications were collected from the patient records and from the Breast Cancer Registry at the Regional Oncology Centre in Stockholm.

Study-specific questionnaire (Study I, II)

A study specific questionnaire was created, based on clinical experiences of experts in the field, pilot tested and modified. The questionnaire concerned demographic data and how the

patient's perceived the hospital stay, information, psycho sociological well-being, body image, social support, perceived pain and health. The questionnaire consisted mainly of statements with a visual analogue scale (VAS, 1-100 mm), to be marked between two anchoring phrases representing extremely negative and positive values. The questionnaire also included a few open ended questions. The questionnaire was answered at three occasions, before surgery, 10-14 days postoperatively, and one year after surgery.

Sense of Coherence scale (SOC) (Study II)

The scale was developed by Aaron Antonovsky, (36) with the intention to measure an individual's comprehension, manageability and perceived meaningfulness in various life situations. In study II the 29 items version of the instrument was used with 11 items measuring comprehensibility, 10 manageability and eight meaningfulness. The items were formulated as statements with two anchoring phrases and the participants were asked to mark a point, between 1-60 mm, on a visual analogue scale (VAS) which best represented their perceptions. The SOC scores from the VAS in study II were transformed into a seven-point semantic scale to facilitate comparison with other studies as this version is mostly used (152). The transformed scores from the 29 items were summarized into an overall score ranging from 29-203; the higher the score the stronger the SOC.

Open ended question in study specific questionnaire (Study III)

The open ended question was part of the study specific questionnaire answered by patients treated in the continuity care model. The question was phrased "Is there anything that you wish for, or would like to change, when you think about your stay in the hospital, and the time after? Write down whatever occurs to you". It was answered ten days after breast cancer surgery.

4.2.1.5 Data analyses

Statistical analyses

The items formed as VAS were treated as interval data. Comparisons within and between groups were assessed by Student's unpaired t-test on approximately normally distributed data and by Mann Whitney's U-test on not normally distributed data. Nominal data were tested by the chi²-test and Fisher's exact test. Internal consistency was tested by Cronbach's alpha with a sufficient coefficient of 0.60 – 0.70 (153). Statistical significance in all calculations was accepted when the p-value was less than 0.05.

Study-specific questionnaire (study I and II)

Fifteen items from the study specific questionnaire were selected to a factor analysis to identify different factors measured and reduce the amount of data. The Varimax Principal Component Analysis with Orthogonal Transformation Solution was used as factor analysis. Factor loadings higher than 0.40 were accepted in the analysis as recommended (153) and four factors were identified (Table III, IV). In study I the four factors and single items were used in comparison within and between the two groups of participants; those early discharged from hospital with drain and those discharged without drain.

To study the effect of the two care models; the established care and the continuity care, on the women's perceptions, multiple linear regression analyses were utilized. The two care models were used as independent variables and the four factors and single items were used as dependent variables. Age, number of days in the hospital, the values of each factor and SOC measured before surgery were used as controls in the equation for their impact on the values at the two follow-ups.

The Sense of Coherence Scale (study II)

In study II the SOC scores were compared between the groups treated in the "Established" and "Continuity care" models. The SOC scores were also included in the multiple regression analyses to study its effect on the dependent variables. The items in the SOC questionnaire were answered by different numbers of patients giving internal missing data.

Open ended question in study specific questionnaire (study III)

Modified constant comparative analysis was used inspired by Grounded Theory (154). All the 97 answers were read through once to get an overall picture of the content. The answers were then read several times and analyzed by open coding based on the words and phrases used by the responders, as described by Glaser (155). The responses could be broken down into several statements which were constantly compared concerning similarities and differences. Categories of needs were formulated and divided into subgroups of satisfied and dissatisfied needs. Each statement was used in one category only. The categories of needs were related to each other, subordinated to a core category and related to two dimensions influencing the satisfaction of the needs (Figure 1 in paper III). The naming of the categories emanated both from the words used by the responders and from the interpretation of the statements. An overall interpretation of the content resulted in two main themes related to the needs. Memos of the analyses was taken by the first author and continuously reviewed.

4.2.1.6 Validity and reliability

Criteria for assessing an instrument's psychometric adequacy are reliability and validity (153). The Study specific questionnaire was developed by one of the authors (HB) and was reviewed by clinical experts who considered the questions adequate for the study which supported the content validity. The factor analyses of the 15 selected items showed acceptable factor loadings >0.40 , for four factors when repeated in two patient samples which would support the construct validity (153). The naming of the factors was done by two of the authors (HB, LB) and is depending on the interpretation of the correlated items (Table III and IV). The reliability of the four factors was tested by Cronbach's alpha coefficient which showed acceptable internal consistency (153) (Table V).

The SOC-scale had shown validity and reliability in several studies (37, 156) and the VAS format had shown to be as reliable as the seven-point semantic scale (152). The SOC scale was used in study II. Internal consistency of the SOC scale was tested by Cronbach's alpha and showed acceptable values being 0.92 in Group 1 and 0.91 in Group 2.

In study III the categorization of the open ended answers were repeated by a research nurse not involved in the study to assess objectivity. An independent classification was performed of one third of the statements into the created categories. The classification was consistent between the researchers in 83% of the statements. This was considered to support the interrater reliability of the analysis (153).

Table III. Result of the factor analysis of 15 items (VAS) in the study specific questionnaire in patients (n=90) in study I.

Items	Emotional perception	Factor loadings		
		Body image	Information-seeking	Social support
After the diagnosis I felt:				
Shocked-calm	0.76			
In despair-not sad	0.75			
Powerless-powerful	0.73			
Dependent on-independent of others	0.47			
Confused-composed	0.87			
Unable-able to handle the situation	0.75			
Worthless-valuable	0.44			
After the diagnosis I thought:				
In detail-not at all				
about my appearance after surgery		0.69		
covering the breast loss with clothes		0.85		
others' opinions		0.80		
After the diagnosis I tried to get information:				
Not at all-as much as possible about				
breast tumors			0.70	
the surgery			0.77	
my recovery			0.71	
My relatives never - always help me				0.82
No one - an endless number of people help me				0.74

Table IV. Result of the factor analysis of 15 items (VAS) in the study specific questionnaire in patients (n=153) in Study II.

Items	Emotional perception	Factor loadings		
		Body image	Information-seeking	Social support
After the diagnosis I felt:				
Shocked-calm	0.84			
In despair-not sad	0.82			
Powerless-powerful	0.76			
Dependent on-independent of others	0.63			
Confused-composed	0.81			
Unable-able to handle the situation	0.75			
Worthless-valuable	0.61			
After the diagnosis I thought:				
In detail-not at all				
about my appearance after surgery		0.81		
covering the breast loss with clothes		0.73		
others' opinions		0.81		
After the diagnosis I tried to get information:				
Not at all-as much as possible about				
breast tumors			0.84	
the surgery			0.82	
my recovery			0.72	
My relatives never - always help me				0.81
No one - an endless number of people help me				0.89

Table V. Cronbach's alpha values for the four factors from the study specific questionnaire.

	Emotional perception	Body image	Information-seeking	Social support
Study I	0.86	0.73	0.82	0.65
Study II	0.85	0.77	0.71	0.74

4.2.2 Project II – Patients' learning and participation (study IV-V)

4.2.2.1 Research design and settings

Study IV and V had a qualitative approach with an interpretative design (150, 157). The women were recruited, between September 2014-March 2015, from one surgical and one oncological department at two hospitals and from one breast cancer survivor organization in Stockholm, Sweden.

4.2.2.2 Participants

Sixteen women with breast cancer were selected. A purposeful sampling was performed to reach variation among participants (157). Inclusion criteria were that the women should have been diagnosed with primary breast cancer and able to speak and understand Swedish. The women were selected due to different age, educational background, professions and country of origin. They were recruited during different phases of the treatment; before surgery, one month after terminated adjuvant treatment with chemo- and/or radiotherapy, one year after diagnosis and two to five years after diagnosis. The women were asked by the health care staff at the departments of the hospital if the doctoral student could contact them to inform about the study. Two women were recruited from a breast cancer survivor organization by the doctoral student. Recruitment and demographic data are presented in Table VI and VII.

4.2.2.3 Data collection

Interviews

Data collection was performed by using interviews, to create knowledge through conversations between the interviewer and the interviewee.

Preparation of interview guide

In the preparation of the interview guide, a pre-study was performed by the first author (LEB) through personal conversations with patient supporters within and outside the health care system. The patient supporters (n=8) were representatives from two cancer helplines (n=4), a breast cancer survivor group organization (n=2), and contact nurses (n=2) within surgical and oncological care. These conversations concerned the opinions of the patient supporters regarding why women with breast cancer contacted them. The conversations were audio recorded and summarized in writing and checked for accuracy by the patient supporters who accepted it to be used and presented. The results showed that women have many unanswered

questions about the disease, treatment, care, medical terminology and body functions. They also need support to manage side-effects of the treatment and their emotional reactions.

Interview guide

The interview guide was semi-structured, and consisted of questions about what and how the women had learned about and understood their breast cancer and its treatment, and how they perceived their participation in their own care (see appendix in paper IV). Due to the results from the pre study, special attention was given to how the women understood their own bodies and the language used in health care. Another effect of the pre study was that the survivor group recommended inclusion of women later than one year after diagnosis. The reason was that the life situation is affected for more than one year after diagnosis which according to the original plan was to be the latest time for data collection. Pilot interviews were performed with three women at different stages of the treatment being before surgery, one year and two years after diagnosis respectively. Minor correction of the interview guide was performed and the pilot interviews were considered to be coherent with the aim of the study and therefore included in the analysis.

Procedures for interviews

All participants were interviewed at one occasion and were informed that they could choose the place for the interview. Nine interviews were performed at the interviewer's work place, five in the interviewee's home, one at the hospital and one in the interviewee's work place after office hours. All interviews started with the question "You are diagnosed with breast cancer. Is that correct?" The purpose was to check that the women's and the interviewer's understandings of the diagnosis were the same. The women were then asked to describe their current situation. The different themes in the interview guide were then followed up, as how the breast cancer was detected and understood, how the information about the diagnosis and treatment was received and understood, which sources were used to get information and how treatment and care were perceived. To reach clarification the interviewer posed exploratory questions as for instance "How do you mean when you say...", "Can you tell me more about that", "What did you think then". Sometimes the interviewer summarized and/or told her interpretation of what the interviewee had talked about to check the common understanding. At the end of the interviews the women were asked about their perceptions of the interview and if they wanted to add anything. The interviews, which were audio recorded, lasted between 0, 30 h to 1, 20 h. Reflections of the interviewer were summarized in writing directly after the interviews. The interviewee was told before the interview that she would have the possibility to ask questions and talk about issues outside the scope of the interview afterwards. This concerned, for instance, questions about care procedures and medication.

4.2.2.4 Data analyses

Qualitative content analysis

Content analysis has been widely used as a measure of analyzing research data both in quantitative studies as in media research, but also in studies with a qualitative approach in the disciplines of nursing and education (158). The method does not belong to a certain

methodology as phenomenology or phenomenography even if there are some similarities with their analytic processes. However, the theoretical assumptions held by Graneheim and Lundman are coherent with the constructivist paradigm (116). Study IV and V do not relate to any specific methodology or philosophy of research but to basic beliefs and assumptions about learning related to the constructivist paradigm (116). The qualitative content analysis was chosen as it is open to both manifest and latent content, and followed an iterative process of going back and forth between parts and wholes of the data and the theoretical assumptions about learning. This process of using theoretical assumptions about learning is related to abductive analysis as presented by Timmermans and Tavory (159). According to the authors we are all influenced by our social and intellectual positions and the researcher should use this in generating creative and new theoretical insights. They argue for revisiting data several times to re-experience it in different ways, to defamiliarize ourselves to reveal objects taken for granted in the back of our minds and finally to case our data in different theoretical frames. They also suggest that researchers should start to analyze small excerpts of data in detail in the light of their theoretical knowledge and try to understand it in as many ways as possible. The analysis of study IV and V was related to this process as described below.

The audio-recordings of the 16 interviews were transcribed by two persons not involved in the research group. The transcribers were experienced in writing patient records and therefore familiar with medical terms, the language and treatment procedures in health care and the importance of respecting the privacy of the patient. The transcripts included pauses, the interviewer's reactions and evident emotional expressions by the interviewee as laughing and crying but without small sounds as mm, ah, sighs etc. as the interview was not aimed for conversation analysis (151). However, these sounds were paid attention to and included in the overall and latent interpretations of the content also noted in the reflections related to each interview. If the answer from the interviewee seemed to have been directed by the interviewer it was not included in the analysis.

The transcripts were checked for accuracy against the audio recordings and few, but significant corrections, were done concerning the meaning of what had been said. Memos were written and revisited during the analysis. The unit of analysis was both the interviews separately, and as a whole, as they were related to each other in an iterative process. The content was analyzed stepwise in both its manifest form, i.e. the participants' descriptions and the latent form, i.e. the underlying interpreted meanings, with the latter as the main focus.

The audio-recordings were revisited repeatedly and each transcription was read several times. A summary of each interview was written and included the interpretations of the women's condition and perceptions to get an overall picture. In the next step seven interviews were selected aiming for variation with regard to time for the interview, age, type of surgery and richness of data for a detailed analysis. Recruitment, treatment, as reported by the women, and demographic data of all participants and the selected seven interviewees are given in Table VI and VII.

Table VI. Time for interview and treatment data. Data is given in numbers for all participating women (n=16) and for the seven interviews selected for an initial analysis given in parenthesis (n).

Time for interview	
Before surgery	3 (1)
1 month after radio- and/or chemotherapy	5 (2)
1 year after diagnosis	4 (3)
2-5 years after diagnosis	4 (1)
Surgical treatment	
Partial mastectomy + SN*	8 (3)
Partial mastectomy + mastectomy + SN or LND**	3 (2)
Mastectomy SN or LND	4 (1)
Bilateral mastectomy + SN + LND	1 (1)
Adjuvant treatment	
Radiation	13 (7)
Chemotherapy	4 (3)
Neo-adjuvant chemotherapy	2 (1)
Anti-hormonal	9 (4)
Anti-bodies	1

*SN= Sentinel node dissection (one lymph node removed) ** LND= Lymph node dissection (several lymph nodes removed)

Each transcription was read meticulously. Text related to the research focus, on learning, understanding and participation, was extracted into units of meaning. The meaning units consisted of sentences and paragraphs and included the interviewer's questions and comments to get a picture of the content and the context. The meaning units were condensed, i.e. the core of the text was summarized in writing. The condensed text was interpreted and labelled by codes which were compared with regard to differences and similarities and grouped into categories. The text in the units of meaning related to the categories were extracted and sorted into each category. The categories and the related units of text were then sorted into what, how, why, and from where the women had learned.

The remaining nine interviews were revisited in the audio recordings as well as in the transcripts and coded openly to complement the findings and identify new codes. No additional codes were identified. Some features were highlighted, as the feeling of uncertainty, which influenced the understanding, and the responsibility of the women in their care. The extracted text in the categories was re-read, the number of categories were reduced by merging those similar to each other. The text in the categories and its underlying meaning was thoroughly discussed by two of the researchers (LEB, CS) based on the interpretations of the transcripts, the audio-recordings and reflections and memos. The interpretations of the text formed themes and sub-themes, answering the question of how learning, understanding and participation proceeded. However, the question about what the women learnt, needed to be included in the analysis, as the content is an important part of learning and cannot be extracted from it, even though it was not the main focus.

All the analytic steps were conducted by me, the doctoral student, in an iterative process, going back and forth between the transcripts, audio-recordings, meaning units, codes and categories. The grouping of codes into categories, the interpretative analysis and the naming of themes and subthemes were discussed and agreed upon with one of supervisors (CS).

Table VII. Time for interview and treatment data. Data is given in numbers for all participating women (n=16) and for the seven interviews selected for an initial analysis given in parenthesis (n).

Age	
34-54 years	7 (4)
55-94 years	9 (3)
Country of origin	
Scandinavian	13 (4)
European	2 (2)
South America	1 (1)
Marital status	
Married/cohabitant	10 (5)
Single	6 (2)
Children	
Yes	13 (5)
No	3 (2)
Residential area*	
Inner city	7 (3)
Low-middle income suburb	3
High-middle income suburb	3 (3)
High income suburb	3 (1)
Educational level	
Tertiary	5 (2)
University	8 (4)
Master	1 (1)
Licentiate	1
Phd	1
Employment	
Business owner	3 (2)
Educator	1
Health and social worker	3
Restaurant worker	1 (1)
Manager	5 (3)
Specialist/Expert	3 (1)

* Source: Statistik om Stockholm, Inkomster i Stockholm 2014. (Statistics incomes in Stockholm) Downloaded 2016-09-09 at: <http://statistik.stockholm.se/attachments/article/155/Inkomstrapport%202014.pdf> and Ekonomifakta at: <http://www.ekonomifakta.se/Fakta/Regional-statistik/Alla-lan/Stockholms-lan/Huddinge/?var=17249>

4.2.2.5 Trustworthiness

Graneheim and Lundman (158) suggest that concepts describing trustworthiness in qualitative research should be used if a qualitative content analysis is performed. They suggest to use the concepts credibility, dependability and transferability, which are intertwined aspects of the concept trustworthiness (160).

In study IV and V the credibility of illuminating the variability of patients' learning and participation was reflected in our selection of interviewees' in various ages, educational backgrounds, professions and treatments. The credibility of data, to answer our research question, was established by the rich amount of data in the interviews and the fact that no

additional categories were identified after the seven interviews had been analyzed. The reflections, written in close connection to the interviews, and the memos during the analysis, helped keeping the analysis close to the data. The judgement of similarities and differences between and the merging and reduction of categories were subject to reflections and discussions between the doctoral student and one of the researchers (LEB, CS) to reach consensus. All the researchers in the group and other research colleagues contributed with different perspectives and thereby ensured increased credibility. The results were presented to different target groups, women with breast cancer, not included in the study, and health care staff in cancer care. All groups found the results to be relevant, recognizable and significant for patient with breast cancer and credibility was thus confirmed.

Interviewing patients with a life threatening disease, as breast cancer, puts high demands on the interviewer for several reasons. One is the challenge to create a safe and trusting encounter, during a short period of time (30 – 60 minutes). The other is to manage feelings, which may come forth, both within the interviewee and the interviewer, without losing focus in the interview. Another is to manage the information from the women, when they expressed a suspicion that they may have been mistreated. It is an act of balance and the interviewing is a continuous learning experience and it that sense the dependability i.e. the changes made over time by the researcher was obvious (158). During the research process, this dependability was discussed with one of the other researchers and minor corrections of the interview guide were made to invite the women to a more open dialogue. Revisiting the audio recordings further helped the review of the interviews and increased my awareness of my approach and interactions. Not all participants were asked all the questions, due to the context, the allocated time and the woman herself.

The transferability of the findings in this thesis is considered to be possible to assess for the reader. The selection of samples and the method for data collection and the analysis have been presented in some detail. The quotations have been carefully chosen to illustrate the interpretations of the subthemes.

4.2.2.6 Reflexivity

Reflexivity is a critical reflection of the researcher on her own positioning in the research process, used mainly in qualitative research (116). It helps to bring values and influences of the researcher on the research process to the light. The preunderstanding of the researcher based on experiences, knowledge, training, values and context, will affect the research questions, methodology as well as the interpretation of data.

I have been striving to have a critical stance through the research process, trying to judge when my background is an advantage to understand data and when it might be a hindrance. Below, I describe my professional background and pinpoint important issues which I have been reflecting on.

I have worked as a nurse for thirty years, mainly in cancer care. I have a formal teacher training and have been working as an educational developer at the Karolinska Institutet for more than a decade.

I was involved in the first project, working as a contact nurse for women with breast cancer, who participated in the project. Beyond my training as a nurse, I have studied psychosocial oncology. My interest in psychosocial concerns of women, directed my research into increasing my understanding of their perceptions of breast cancer care. As my knowledge and interest in pedagogy increased, I became interested in studying how learning theories could help us improve our understanding of cancer patients.

My experiences and knowledge have helped me understand the context and the disease during the interviews and when analyzing the data in project II. On the other hand, this could have hindered me from asking follow up questions and made me take things for granted in the analysis. Some situations, which occurred during project II, exemplify my development related to reflexivity. When I constructed the interview guide for study IV-V, I included a question concerning the present well-being of the women. This was not the focus of the project. After reflecting together with one of my supervisors, I realized that I was still approaching the research from a psychosocial perspective. During the interviews, I sometimes discovered, that I asked questions as if I were a teacher. When I realized that I stopped. In some instances, I told the woman about my sudden awareness of my approach and then I changed the way I performed the interview.

During the analysis, I was overwhelmed by the rich amount of data. In the beginning I looked upon the data through my psychosocial lenses. I became aware of this, when I discussed the data with my supervisor, and I continued the analysis using pedagogical lenses instead. This meant that I deliberately searched for expressions of learning and understanding in the data. Even if it is the same data it was cased in a new theoretical frame, being my pedagogical understanding. This in accordance with the abductive analysis as described by Timmerman and Tavery (159).

During both projects, I have continuously discussed my research at seminars with other doctoral students, researchers and supervisors. This has contributed to varying perspectives on the analyses. The interpretation of data, in project II, has been discussed with my supervisors, other researchers, doctoral students, patients and health care staff to get feedback and new perspectives. The supervisors represent the practice and research fields of medical education, nursing and breast cancer surgery which also have contributed to different perspectives.

4.2.3 Ethical approval and considerations

The research protocol of study I-III was approved by the Ethics Committee of the Karolinska Institutet, and of study IV and V by the Regional Ethical Review Board in Stockholm. All studies were performed in accordance with the World Medical Association of Helsinki Declaration (161). The participants in the studies obtained written informed consent in

accordance with the Personal Data Act (162). Study IV and V required and had approval by the Controller of Personal Data at Karolinska Institutet. Permission to recruit patients was obtained from the heads of the departments. The participants were informed about voluntary participation and the possibility to withdraw at any time, without consequences for their treatment and care. Confidential treatment of data was guaranteed.

I, the doctoral student, made all the interviews. I have a former training in and long experience of meeting and talking with patients in treatment for cancer. Attention was given to the women's vulnerable situation and if signs of inconvenience would appear during the interview, it would have been interrupted, but this was never the case.

There is a risk that patients who are in a vulnerable situation feel obliged to accept to participate in research studies as they are dependent on the staff. I was acting both as a contact nurse and researcher in study I-III, which might have affected the women's participation. However, one year after diagnosis, when we did not have any contact, the response rate was still high which suggests that the patients participated by free will.

I was not engaged in the care of the women in study IV and V, and consequently they were not dependent on me. However, the interviewing might open a close connection and emotions as crying, sadness, anger and joy are expressed and sometimes terrible stories are told which can affect me as an interviewer. The vulnerable situation of the patients is demanding during interviews and my previous experience in meeting cancer patients helped me manage my own feelings, but also to adjust the conversation. My impression from the interviews was that the women needed to talk. They wanted to process their experiences, sometimes they wanted an advice or an incentive to change something. The possibility of withdrawing as participant was emphasized, in the beginning and at the end of the interview, but none chose to withdraw. In some cases mistreatment of a patient could be suspected. If the woman wanted help, I supported her by informing her about where she could turn for help, but I did not interfere in the care. In some cases the women contacted me for telling me about the outcome.

5 FINDINGS

5.1 PROJECT I – PATIENTS’ WELL-BEING (STUDY I-III)

5.1.1 Effects of voluntary early discharge from hospital (study I)

Of the 118 participating women 28 (24%) were discharged with a drain in place. Their median hospital stay was reduced by four days, compared to the 90 women, who stayed until the drain was removed. Further comparisons with the latter group showed that those with an early discharge were younger, fewer women lived alone, and more were diagnosed with stage I cancer, and had been treated with breast conserving surgery. This group desired a shorter hospital stay, had received more information about self-care, was more concerned about the body image and sought more information one year after the surgery. No other differences were found between the groups concerning their self-rated perceived well-being, postoperative complications or satisfaction with the general treatment from staff at the hospital. Both groups reported similar problems, in an open ended question, after the return home, concerning inconveniences of the arm and/or drain on the operated side causing problems when lying in bed, handling the personal care and getting dressed. Those who stayed at the hospital until the drain was removed, also perceived fatigue and loneliness.

Early discharge from hospital was feasible, based on an individual assessment of the needs of care and information of the patients. Access to health care staff, e.g. a contact nurse, is necessary for patient’s safety, self-care and well-being after the hospital stay.

5.1.2 Effects of continuity care, short hospital stay and SOC (study II)

Patients treated in an “Established care” model (Group 1, n=29) were compared with those treated at a breast clinic in the new “Continuity care” model with a reduced hospital stay (Group 2, n=115). The effects of the models and SOC were studied. Group 2, preferred a shorter hospital stay, rated better general health and SOC before surgery compared to Group 1. One year after surgery, Group 2 rated less immediate postoperative pain, better emotional and mental well-being than Group 1. More patients in Group 1 had removed their breasts compared to Group 2. Patients in Group 2 had their drains in place for a shorter period of time, developed more seromas and had one day shorter in-hospital stay time. No other differences were found between the groups concerning age, cohabitants or stages of the disease. The length of the hospital stay did not have any effect on the patients’ evaluation in any of the variables except for the length of the stay. The longer the duration of the hospital stay, the more it was evaluated as having been too short. In addition, those with a stronger SOC preferred a shorter hospital stay. Stronger SOC also had an effect on a more positive evaluation of the sexual function, trust in treatment, general health and mental well-being. Increasing age was related to positive evaluations of well-being, trust in treatment and satisfaction with the care. The most significant effect on self-rated well-being after surgery was the self-rated well-being before surgery, i.e. those who rated better well-being preoperatively also rated better well-being in the same variables at both times postoperatively.

It was concluded that a care model with high continuity between the patients and the health care staff in a setting with short hospital stay after breast cancer surgery may have a positive influence on the patients' well-being. The continuity may increase the possibility for an early individual assessment of the patient's well-being, SOC and needs of information and identifying those in need of specific support.

5.1.3 Needs of care in a setting of short hospital stay (study III)

Of the 132 participants cared for in the "Continuity care" model, 97 answered an open ended question about their needs, 10 days postoperatively. This concerned the care received at the breast clinic and the surgical ward, as well as the time at home after the hospital discharge. The answers consisted of 150 statements which were coded into five categories of needs: Information, Practical assistance, Personal treatment, Emotional support and Trust. The dimensions of time and space could be related to some of the statements. The categories were based on the manifest content i.e. what was stated and the content in some statements was interpreted, i.e. the latent content was classified into a category, especially in the core category Trust. The categories were divided in satisfied and unsatisfied needs and are summarized below.

5.1.3.1 Information

The pre-and postoperative conversations and the accessibility of the staff at the breast clinic contributed to satisfy the patients' needs of information. Unsatisfied needs of information concerned self-care, available support at home, physiotherapeutic instructions, further treatment and information given to relatives.

5.1.3.2 Practical assistance

The patients expressed their need for practical assistance with personal care, pain relief and physiotherapy during the hospital stay as well as after the return home. Initiatives taken by the health care staff to meet these needs without the patients' explicit request instilled feelings of comfort and trust.

5.1.3.3 Personal treatment

The patients expressed gratitude for the sensitive, gentle and personal treatment they received from the health care staff. Disrespectful treatment and lack of confidentiality were described by some participants causing feelings of being objectified. Having too many members of the staff at the surgical ward involved in the patient's care also caused dissatisfaction.

5.1.3.4 Emotional support

Emotional support from the staff, such as consideration and understanding, was appreciated and wished for, but not always given. The preparatory and concluding conversations with the staff at the breast clinic were felt to be emotionally supportive.

5.1.3.5 Trust

The skills, continuity and accessibility of the staff at the hospital contributed to the feeling of trust. The contact nurse at the breast clinic created a feeling of security as she was easy to reach and knew the patient. When information was considered being faulty or promises were broken, it reduced the trust in the staff.

5.1.3.6 Time and space

Time affected the fulfillment of other needs. When the hospital staff spent time with the patients it was appreciated and the opposite caused feelings of being treated as an object. The time, between the preoperative preparation and the surgery, was often four days, which was considered to be both too long and too short. Longer hospital stay and visiting hours for relatives and friends during the stay with the possibility for privacy were desired by some.

5.1.3.7 Relationships between categories of needs

The five categories of needs - Information, Practical assistance, Personal treatment, Emotional support and Trust - were incorporated into a conceptual model to illustrate the relations between the needs and the dimensions of time and space (Figure 1 in paper III). It was assumed that satisfied needs of information, practical assistance, personal treatment, and emotional support would contribute to feelings of trust in the care given, but also to the patient's own ability to manage the situation.

It was concluded that if the patients' needs are confirmed and satisfied, this can create feelings of trust and security. The continuity with and the expertise of the nurses to assess the patients' needs were stressed, especially in a setting of short hospital stay.

5.1.4 Summary of findings from Project I

The effects of a short hospital stay after breast cancer surgery in combination with high staff continuity showed feasibility. The continuity with staff could have a positive influence on the well-being of the women if the needs of the patients were met. The continuity may also increase the possibility for an early individual assessment of the patient's well-being, SOC and needs of information and identifying those in need of specific support.

5.2 PROJECT II – PATIENTS’ LEARNING AND PARTICIPATION (STUDY IV-V)

The findings of study IV and V show characteristics of breast cancer patients’ experiences in terms of learning, understanding and participation. An overview of the findings in study IV and V are presented in Table VIII and IX.

5.2.1 Patients’ learning and understanding (study IV)

The interpretation of the interviews with women during their breast cancer trajectory uncovered the following themes describing the features of their learning processes and understanding: *Interacting with a diversity of information*, *Concealed and expressed understanding* and *Struggling to understand and manage the new life situation*. The themes and subthemes are presented below and in Table VIII.

Table VIII. Patients’ learning illustrated by themes and subthemes.

Interacting with a diversity of information	Concealed and expressed understanding	Struggling to understand and manage the new life situation
a. Intentional information given or sought b. Unintentional information from bodily sensations and events	a. Cognitive, emotional and management dimensions of understanding b. Concealed understanding c. Expressed understanding	a. Preunderstanding in a meaning making process b. Intrusive and intimate driving forces behind learning c. A desire for contemplation and dialogue

5.2.1.1 *Interacting with a diversity of information*

Our findings show that women diagnosed with breast cancer, need to interact with a vast amount of information from many different sources. In addition to the intentional information received from health care and their own searching, they need to deal with information unintentionally coming from sources they are not in control of, i.e. their body and events in- and outside health care. These sources turn out to be very important in the process of creating understanding, and are presented in the subthemes below.

Intentional information given or sought

The oral, written and instructional information given by different professions in health care is greatly appreciated. A combination of the various forms of information and the staff answering questions and checking the understanding of the patients support their learning. Extensive, irrelevant or frightening information is a barrier for learning. Women search for information from many sources, such as the Internet and in conversations with health care professionals and people in their surroundings. The sources on the Internet are found to be helpful to fill information gaps. It concerns for instance detailed information about the disease and treatment, the body appearance after breast reconstruction, cancer prevention, dietary

advice and how to talk to children about cancer. Sometimes, however, the information is frightening and stops further searching. Some women search for as much information as possible and then try to sort out the most relevant. Sharing the breast cancer experience with others is appreciated by some women, but is avoided by others who don't want to identify themselves with the disease or talk about it.

Unintentional information from bodily sensations and events

Unintentional information is the women's perceptions of sensations from the body and from being part of events within and outside health care. All senses are activated and information is gathered through the ears, eyes, nose, mouth, hands, skin, nerves and the visceral body. Body and mind are absorbing and interpreting stimuli from bodily sensations and events in an ongoing process. Examples of information absorbed by the senses are seeing one's own ultrasound-photos of the breast, hearing numbers mentioned during radiation therapy, smelling the odour of chemotherapy, feeling changes in the skin or in the taste of food, perceiving pain or nausea and own or others palpating of the breast. Examples of receiving unintentional information from being part of events are the noticing of sudden changes in the staff's behavior, watching TV and seeing or hearing about others' experiences of cancer.

5.2.1.2 Concealed and expressed understandings

The interpretation of the information results in various understandings which can be concealed or expressed. The content of the understanding relates to all aspects of the disease and treatment including the care and one's own life. The cognitive, emotional and management dimensions of understanding are intertwined, but depending on the situation, one dimension could be dominating. The three subthemes describe the dimensions of understanding and concealed and expressed understanding.

The dimension of understanding - cognitive, emotional understanding and manageability

In common for all women, understanding comprises cognitive and emotional dimensions and manageability which can be coherent, contradictory, double edged, conflicting and dominated by one dimension. All women understood cognitively, that they had been diagnosed with breast cancer, but with a great variety regarding the depth of understanding. Some could tell in detail about their specific cancer, some could tell the name of the type and/or the stage of the breast cancer, some could not but understood that their cancer was "bad" or "good" even though it was not clear to them what it meant. If the physician imparted hope, emotional understanding dominated even if the cancer type was the "worst" kind. Sometimes the emotional understanding of losing control was dominating resulting in distrust of the own body and sometimes the management of side-effects was dominating. One important part of learning was changed understanding of one self and one's own life. Bodily changes due to the treatment as loss of energy, a breast or the hair and the side-effects of anti-hormones as depression, dry mucous membranes and joint pain were all described as affecting this understanding sometimes expressed as "I don't recognize myself". In addition contradictory cognitive and emotional dimensions of understanding complicated the overall understanding.

For some, the experience of breast cancer contributed to personal development and changes in their lives. The learning also concerned the understanding of the health care system.

Concealed understanding

Concealed understanding came to the fore as an important finding. It means that the women don't show their understanding in any way, others don't notice it or the women themselves are not aware of it. The reason for the women to conceal their understanding intentionally is to protect others, including the health care staff. The understanding can also be unintentionally concealed when the women misinterpret symptoms or a situation and don't contact the staff for help or information. When being parts of events in health care, the women are highly aware of what is happening. The staff's verbal and non-verbal expressions are interpreted and sometimes the women understand they have cancer before anyone has told them. The shocking insight of having cancer switched off listening, was perceived "as a sudden filter", and blocked the possibility of assimilate the following information. When the women don't show their understanding, through emotional or verbal expressions, or the staff does not pay attention to it or understand the women's interpretation, the communication is broken.

Expressed understanding

When the women express their understanding by talking, showing emotions or skills, the understanding becomes possible for the staff to notice. The cognitive understanding is expressed during consultations with the health care staff, in emails or as prepared lists of questions. Emotional expressions as crying, showing anxiety or worries are other ways of demonstrating understanding. Expressed manageability is the women's demonstration of their skills e.g. palpating the breasts or massaging the arm to ease lymphedema.

5.2.1.3 Struggling to understand and manage the new life situation

This study shows that women struggle to understand what is happening to them, from the time the tumor is detected, until the end of treatment with anti-hormones five years later. The understanding is influenced by the pre-understanding of the women, their driving forces behind learning, and the possibility of contemplation and dialogue with health care staff.

Pre-understanding in a meaning-making process

The preunderstanding is based on the women's previous knowledge, assumptions and experiences and affects their interpretation and understanding of their current situation. This was illustrated by the women's explanations about the disease and treatment, e.g. the cause of their breast cancer and adverse reactions. Self-understanding is an important part of preunderstanding and affects the approaches of the women to learning, life and to how they manage their situation. Women with a great need of control related to an approach to search for all information they could get regarding how to improve well-being. The approach of being satisfied with the information received from staff reduced the need to search for information elsewhere.

Intrusive and intimate driving forces behind learning

The driving forces behind learning are both intrusive and intimate as breast cancer concerns body and life. Before surgery the intrusive drivers are to understand how to prepare for the operation and for participating in decision making about treatment and research studies. Other examples of intrusive drivers are the need to understand the expected bodily effects of treatment and self-care. Body sensations before, during and after treatment are intimate drivers behind learning and searching for information. The aim is to understand and take control over one's well-being and do something on your own, like "What can I do? How can I help here?" Some want to get information directly and not be wrapped into a hope that does not exist. This facilitates the process of mental preparation for the treatment. The drivers for learning may change over time depending on what is considered to be the most relevant information in the current situation. Curiosity can be aroused a long time after the treatment is terminated as for instance, during the interview.

A desire for contemplation and dialogue

The women need time for contemplation and dialogue with health care staff and others. In the dialogue a possibility for questions and feedback is asked for, which facilitates decision making and self-care. To have access to a contact nurse at the hospital feels safe, as the women can visit the nurse to check body symptoms and ask questions when they need. Support from nurses and physicians are especially important when contradictory information about treatment options is delivered, making it difficult to understand and decide about the best choices. Sometimes it is difficult to formulate questions to the physician during the consultation – "You know what to ask, after you have left the room". Emotions have a great impact on how women make sense of information, both to what and how it is communicated. Verbal and nonverbal information can be delivered in a calm and positive way which communicates hope. When it is delivered in an unclear, insensitive or dramatic way the women are frightened. Other obstacles to understanding are reduced attention, at the time of diagnosis, and the perceived impaired memory due to the crisis and treatment. Time is needed to assimilate and process the information both cognitively – "What did they say, what does it mean?" - and emotionally – "Help, I am going to look butchered"!

5.2.2 Patient participation in breast cancer care (study V)

The following themes describe the perspectives of patient participation: *Respectful and personal encounters*, *Part-owner in decision making*, *Striving to manage treatment, care and self-care*. Themes and subthemes are presented below (Table IX).

Table IX. Patient participation illustrated by themes and subthemes.

Respectful and personal encounters	
Part-owner in decision making	Striving to manage treatment, care and self-care
a. The women expect to receive information and staff to take decisions	a. The women are compliant with the treatment plan
b. The women have a dialogue with staff to make decisions	b. The women do not know what to do
c. The women expect active participation in decision makings	c. The women take own initiatives and decisions

5.2.2.1 *Respectful and personal encounters*

Respectful and personal encounters were found to form the basis for the patient's perceived participation. When the staff treated the women with respect and kindness, took time to listen seriously to the women's concerns and met their worries, it contributed to a feeling of being "seen" as a human being. When the patients received explanations and demonstrations of procedures in a calm and personal manner with a possibility to ask questions in privacy, it facilitated their participation. A well-planned organization was perceived as safe, albeit, at times, somewhat impersonal.

5.2.2.2 *Part-owner in decision making*

All women want to be part-owners in their treatment and care, to varying degrees, as illustrated in the three subthemes. The subthemes do not represent different individuals but rather different approaches which can be taken by the same woman depending on her current needs and the type, time and situation of the decision.

The women expect to receive information and staff to take decisions

To be part-owner in this regard, means to receive information from the experts who make the decision for the women. The women consider themselves unable to make decisions about treatment and care. Lack of knowledge, vulnerability and emotional reactions are reasons behind their inability to make big or small decisions.

The women have a dialogue with staff to make decisions

Another form of perceiving part-ownership is when decisions are made in consensus with the staff. The women get worried when they do not understand what the best choice is and

they need to discuss the options and its consequences several times with the staff to be able to be part of the decision making.

The women expect active participation in decision making

The most active form of part-ownership concerns the decision making regarding the surgical and adjuvant treatment, the follow-up and rehabilitation. The women prepare themselves before the decision-making by gathering a variety of information including research, talking to others with and without cancer experiences, inside and outside health care. After contemplating different options and making a choice the women inform the staff. When the decision of the women is acknowledged it is appreciated as a respectful and personal treatment. The dialogue with staff is essential in the decision making, as the disease and treatment means uncertainty. Sometimes the women take initiatives of their own to the dialogue, sometimes they feel they are left alone with the decision as no one can give an advice and sometimes they take a decision against the recommendations. When the women's decisions or desires are not respected or met, they perceive a lack of trust and no participation. Contradictory and complex information complicate the decision making, especially in the vulnerable situation of the women, who are forced to assimilate and understand a bulk of information, during a short period of time, in order to make the best choice.

5.2.2.3 Striving to manage treatment, care and self-care

The participation in self-care can be forced upon the women especially in the context of short hospital stays. A strong driver for the women to participate in managing the effects of treatment is to increase their well-being and take control over the situation. Information about self-care is considered to be an important part of the participation. Different levels of understanding and approaches to participation are described in the subthemes below.

The women are compliant with the treatment plan

Characteristic of this subtheme is that the women follow the treatment plan, even if they sometimes are hesitant to it, because they understand that it is necessary in order to cure the cancer. Sometimes the women persuade the staff to continue the treatment despite dreadful side-effects and sometimes the women are convinced by family or staff to continue the treatment.

The women do not know what to do

This subtheme illustrates women's perceptions of bodily sensations, such as early and late side-effects of treatment, which they do not understand or know how to handle. At first they do not contact the staff as they think there is nothing to do. Sometimes the staff does not recognize the problem and hence cannot help. When the treatment affects the women's health in multiple ways, e.g. diabetes, anxiety, obesity, they sometimes do not know where to seek help and need to visit different care givers. A more cohesive care is requested.

The women take own initiatives and decisions

This subtheme demonstrates the need of the women to understand what is happening in their bodies. Their own initiatives to perform self-care and influence their care come to the fore. The reasons are to improve their well-being and gain control over the disease. Insufficient and unreliable information and ideas about staff's inability or lack of interest are other reasons for own initiatives. The understanding and continuity of the staff is needed for the women's participation in accomplishing safe care. A summary of facilitating factors and hurdles in the women's participation are presented in Table X.

Table X. Facilitating factors and hurdles for the participation of women in their breast cancer care

Facilitating factors	Hurdles
Personal and respectful recognition	Lack of personal recognition
Dialogue with staff who listens, answers questions, demonstrates, explains in a calm way	Lack of privacy in the hospital – a barrier for dialogue
Understanding the treatment, available options and consequences	Preunderstanding or lack of understanding the treatment, available options and consequences
Need for control and well-being a driver for self-care	Lack of understanding bodily sensations and self-care
Time to prepare oneself by reading, thinking, talking with others	Lack of time to assimilate, process and understand information
Preunderstanding of the patient	Preunderstanding of the staff
Self-confidence to fight for one's cause	Language barriers in the staff
Trust in the staff	Distrust in the staff - not listening, withholding treatments, ignorance
Well-planned efficient care	Mistakes and discontinuity in care and treatment

6 DISCUSSION

6.1 CHANGES IN BREAST CANCER CARE AND PATIENTS' WELL-BEING

The first part of this thesis is from the early days of the international development of short hospital stay programs after breast cancer surgery. Study I was one of the first reports evaluating women's well-being after early discharge from hospital. The findings of study I showed that older women living alone preferred to stay longer in the hospital. It was stressed as an important finding as it demonstrated that early discharge from hospital was not feasible for all (163). In study II the women who preoperatively, rated a higher SOC preferred a shorter hospital stay. They also rated a better emotional well-being and health before and after surgery. Those who had a longer hospital stay wanted to stay longer in the hospital. An interesting finding in study II was that women who rated a stronger SOC, also rated better health, mental well-being and trust in the treatment which was in accordance with others (37-43). In a recent study higher SOC was found to be a predictive factor for lower risk of progression and mortality among women with breast cancer (164). It has been discussed if SOC is possible to increase. In one study, the patients' SOC could be strengthened through education (165). However, in a more recent study SOC showed stability over three years in women with breast cancer, which supports the theory of SOC as being a stable trait, rather than a capacity which responds to training (166). These results are discouraging as they indicate that comprehensibility, meaningfulness and manageability of an individual cannot be strengthened. Considering that the SOC scale measures the global attitude to life and not the understanding of the individual, it cannot be used to evaluate learning experiences. However, it would be interesting to study if the SOC is related to learning, understanding and participation.

In Sweden, the majority of patients adhere to short hospital stay, i.e. returning home the same day, or the morning after the day of surgery. This puts high demands on staff to support the women, and on the women to care for themselves. Considering the previous findings, older women living alone and those with poor health, SOC and well-being need special attention. Short hospital stay programs are continuously implemented and evaluated demonstrating cultural differences (167-174). A recent study from India found, that women after returning home from hospital were more dependent on family support compared to studies from Western countries (174). The continuity of care and access to a breast cancer nurse are factors considered to make the short hospital stay possible in Western countries (169). These findings are coherent with those reported in this thesis.

When the women expressed their wishes regarding their breast cancer care in study III, their needs of practical, emotional and informational support were made obvious. In some cases the needs of the patients were met and in some cases not. The continuity with the contact nurse, the surgeon and the assistant nurse at the breast clinic contributed to satisfying the needs of the patients and to the feeling of being personally recognized. Unmet needs of information, psychological and physiological support are still mayor concerns in breast cancer care (5, 13, 76). The continuity of care is since long recognized as an essential part in

cancer care (2-4). Continuity of care, includes not only the trusting relationship with staff, but also to have access to continuous care over time and that the patient is known (175). The role of the contact nurse has been acknowledged in many countries (176-180). Since 2015 contact nurses were introduced as a quality indicator in breast cancer care in Sweden (20). The need for support in coping with the illness experience may prevail for a long time after diagnosis, at least for five years as shown in study IV and V and by others (13). However, this can be difficult to realize considering the time constraints in health care, shortening the encounters between health care staff and patients. This calls for a closer collaboration with out-patient primary care. Patients also benefit from preoperative education which can reduce anxiety, increase knowledge and satisfaction (102). It can be concluded that early discharge is well-accepted and found feasible as long as the patients' needs of support and learning are met.

6.2 PATIENTS' LEARNING, UNDERSTANDING AND PARTICIPATION

Today short hospital stays are taken for granted and is implemented for a number of other diagnoses as well. The global and national call for increasing patient participation to improve health care brings new questions to the fore (127, 181, 182). What does participation mean from the perspective of the patient? What is required and how is it enacted in today's short clinical encounters? These questions are in focus in the second part of this thesis and constitute a follow up of the introduction of early hospital discharge.

In Project II patient participation is regarded as two sided – as a possibility or a necessity. The patients' understanding of the disease, treatment and care are prerequisites for participation. The project takes its point of departure in the perspective of the patient as a learner and from theories of learning. The learner is viewed as an active participant who process information to create an understanding, individually and in interaction with others and the environment (119). As learning is a complex phenomenon several theories of learning are used in the following to explore and explain the findings in project II. Patients' learning and understanding as found in study IV is presented by the subthemes in Figure 2.

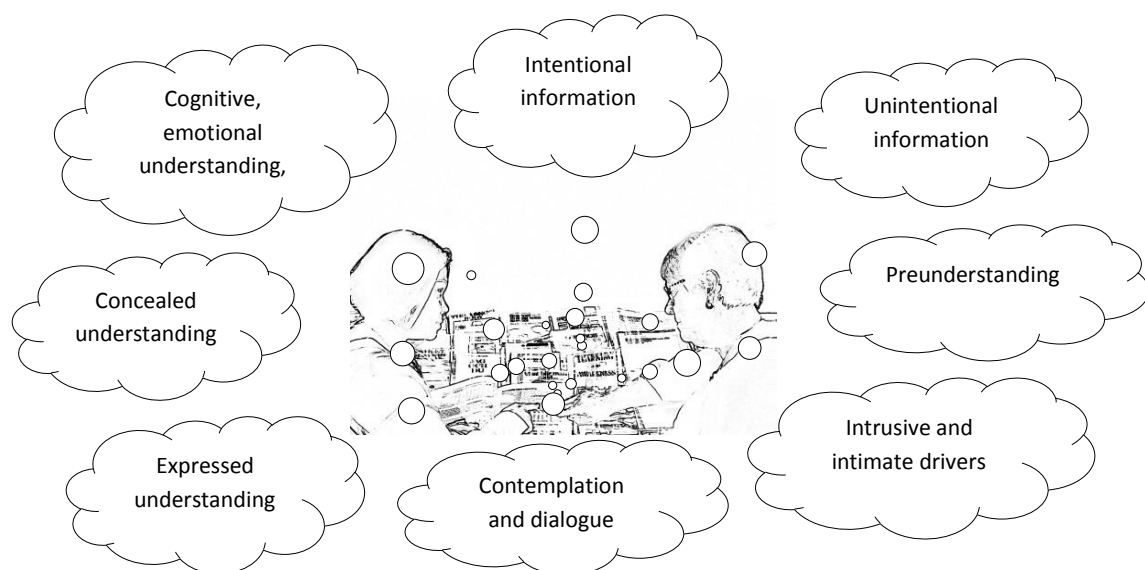


Figure 2. Patients' learning and understanding illustrated by the subthemes in study IV.

Some of the most important findings in study IV and V are that preunderstandings and interpretations of bodily sensations and events have strong impact on the understanding of the women. To make participation in treatment and care possible, the women need time to assimilate and process information, in a supportive dialogue with staff, to create understanding. Their concealed understanding needs to be explored. This is paramount for the women's well-being and coping with the illness and life.

6.3 PATIENTS' LEARNING RELATED TO THEORIES OF LEARNING

The present study on patient learning show commonalities with learning in general but also that learning as a patient takes on special features which are important to understand. All learners need to process the content of what is supposed to be learnt. Preunderstanding affects this process which results in varying understanding between individuals (117, 119, 120, 124). This was also true for the women in study IV and V.

Being informed is not the same thing as learning, although information constitutes the content part of learning (119). In this thesis, information comes to the fore as the verbal and non-verbal communication. A significant finding is the importance of information coming from the patient's bodily sensations. The content of the women's learning is therefore characterized by all these forms of information. Further, the interpretations of the information could be related to the women's preunderstanding, as for instance a new lump in the breast is interpreted as benign as previous lumps were. The health care staff was not always aware of what constituted the content for learning, i. e. what kind of information the women absorbed through their senses, for instance from bodily sensations or by being part of events. Neither were the women's preunderstandings and interpretations of the information obvious to the staff when the women did not express it. These findings indicate an urgent need of increasing the understanding in health care about the factors which influence the women's learning and understanding.

6.3.1 Drivers for learning

The drivers of the individual for, and ability to, acquire information and their interactions with the environment are basic elements in how the learning proceeds (117, 119, 120). In contrast to students, learning is forced upon the individual when diagnosed with breast cancer. The drivers for learning are therefore both intrusive and intimate as it affects the individual's body and life situation. Those drivers are, for instance, the need to know how the body will appear when the breast is removed or replaced by an implant, to manage side-effects of the treatment, prevent relapse of the cancer, improve one's well-being and chances to survive, and how to talk to family and friends. Ryan and Deci (183) distinguish between extrinsic motivation which responds to external demands, while intrinsic motivation represents the drivers within the learner. The latter has proved to result in high quality learning, whereas learning from external drivers varies in quality.

In contrast to student's learning the intrinsic drivers of patients are not based on enjoyment and free will to learn, but rather on constraint and the need to understand how to handle the

situation and increase their wellbeing. Therefore these drivers might rather to be considered as external demands to learn. As shown in study V, a strong factor for participating was to understand how to get control of the situation and the bodily sensations. Supporting students as learners, to enhance their feelings of competence and autonomy is assumed to increase their motivation and self-determination (183). The same support to patients also needs attention. The drivers can facilitate learning as “I need to know how to manage the side-effects” and the staff can help. Fear however, might be a barrier to assimilate information and the staff sometimes needs to focus on emotional support, instead of motivating the patient to learn.

Sometimes the driver to understand is ambiguous, as described by the women who both wanted and did not want to know about the survival rate. This illustrates that a breast cancer diagnosis evokes questions concerning life and death, but doesn’t necessarily mean that you are ready to learn about and deal with such questions. Our findings also suggest that there are no groups of women who want to know and others who don’t want to know. The drivers for understanding are shifting due to the individual, the current situation and what the women consider is relevant. The way information is delivered, also affects understanding, and may pass on information, not asked or being prepared for. This was exemplified when someone in the staff asked with a dramatic voice “Do you know that you have a very serious disease”? The findings in study IV and V indicate that there is a need for continuous and sensitive assessment of the patients’ drivers for learning.

6.3.2 Meaningful and transformative learning

The content of learning needs to be relevant for, and coherent with, the current needs of the women in the living present. For instance, information about breast prosthesis is not desired or asked for when the breast is not going to be removed. The relevance varied between individuals as shown in study IV. Some women were satisfied with the information they received from health care. Others searched for and wanted all the information they could get in order to choose the most relevant. The relevance of the content is one of the most important drivers for a meaningful learning as pointed out by Knowles, Marton and Booth among others (117, 118). Therefore, the relevance of the learning content needs to be paid attention to in health care.

For some women, the experience of having breast cancer, meant a changed view on life as shown in Study IV. For instance, how the family or work were prioritized, doing things which make them feel happy etc, which is in accordance with others (6-12). The findings can be compared to the theory of transformed learning, which includes critical reflection on one’s own assumptions, changing beliefs and acting on new understanding (120). Mayer (121) states that the learner also needs to use cognitive processes as interpreting, comparing, summarizing, and explaining to create understanding and transfer it to other situations. Transferred learning is exemplified by the women in study IV who used critical reflection on physicians’ assumptions, assessed and compared information from different sources including research, about treatment with anti-hormones, and questioned its relevance. To be

able to decide about the treatment the women required a dialogue with the physicians about the effects and side-effects of for instance anti-hormonal treatment, and the consequences if they dropped out of the treatment. If this need was not met the women became uncertain and worried about their decisions. The findings highlight the role of the health care staff as facilitators of patients' learning. A space for reflection and dialogue seems necessary to support the understanding of the patients which is in accordance with others (96, 108, 113).

6.3.3 Learning through variation

In the theory of variation, learning is described as the discernment of something different, which is captured by the individual's awareness (122). This is exemplified in study IV by the women who perceived something new in the body as a lump in the breast, skin sensitivity after radiation or pain from chemotherapy. When the information from the body did not agree with the information received from health care, it caused anxiety and confusion. The women did not understand what was happening or how to manage their bodily sensations. In some cases the women did not contact the nurse at the hospital as they thought the nurse could not help. Instead they tried out solutions on their own, for instance what to eat when everything had a disgusting taste. According to the theory of variation and that bodily sensations vary between women, and for a long time after treatment completion, one could argue for giving information about all variations of side-effects to all women. However, as learning is supported by the relevance of the content for learning, (117) this creates a dilemma. The dilemma is that the women need to be prepared to manage their situation for a long time after the treatment is completed but need the information only when it is relevant. The contact nurse may meet the needs of information and support during a certain period of time, during the first phases of treatment. However, as shown in study IV and V, some patients had questions and worries about their treatment and health, as long as five years after their diagnosis.

The theory of variation can also contribute to shed some light on women's perceptions of the surroundings (122). Changes in the behavior of the staff during a clinical consultation are variations which are interpreted by the women. Examples of such variations are when the staff suddenly starts to talk with a soft or childish voice, tilting the head, patting the woman's head, or mumbling when examining the breast. These variations were noted by the women who interpreted them as signs of having breast cancer. Sometimes this was correct and sometimes not. The interpretation caused anxiety, which hindered the women from assimilating further information. If the women concealed their interpretations, no one could pay attention to them. Feedback could not be given until the women expressed their understanding verbally or emotionally. This exemplifies the significance of the patient's interaction with the staff to get support during the learning process. The staff may not be aware of their own behaviors or how they are interpreted by the patients. In addition, the awareness of the women is not always directed to the same content of learning as the one the staff is aiming for, and meaningful learning is not supported (117). The women's awareness

of differences in the current situation needs attention from the staff in order to facilitate the women's understanding.

6.3.4 Learning through the lived body

Another important source of learning, in study IV, was the women's perceptions of their own bodily sensations, which were interpreted in relation to their pre-understanding. The findings can be understood in relation to the phenomenology of perception presented by Merleau-Ponty (1962). He states that learning about the world is to perceive and process a variety of stimuli through the body and to internalize the new understanding as a part of one self. He also claims that the body is not an object which can be understood in its parts, as all parts are intertwined and there is no other way to learn about the world than to perceive it through the body.

Leder (1990) agrees with this view, and calls the incarnation of our experiences the "lived body" - it is through the body we live and learn. He argues for an increased attention to concealed phenomena, such as the patients' perceptions to promote their well-being, rather than treating patients as objects. Patients' feelings of sometimes being treated as objects were also found in study III and IV. The "Absent body" as described by Leder is a phenomenon which also influences the patients' learning (1990). In study IV the absent body was exemplified by the women who perceived a filter blocking their ability to hear what was said, after they had received their diagnosis. The inability to hear could be described as a "dys-appeared body", i.e. a dysfunctional body which comes to the fore of the individual's awareness, as the body disappears which makes it impossible for the women to hear the following information. If this is ignored by those who provide the information, it will not be assimilated by the patient. Another example, of a dys-appeared body was a woman who perceived that she belonged to the 5%, who got all the bad things. Several times, before the surgical, as well as the adjuvant treatment, she was informed that she probably would not get the unusual treatment, as only 5% of all women got it. After the examinations of her breast tissue it turned out that she needed the unusual treatment. She understood she could not trust her body anymore - it had disappeared from her control - and wanted someone else to tell her if she was healthy or not. It can be assumed that the staff's intention of informing patients about the most common treatment is to instill hope and trust. However, as demonstrated in the previous example, it had the opposite effect and contributed to feelings of distrust of the body and maybe also to the information delivered by the staff.

6.4 ENCOUNTERS FOR LEARNING AND PARTICIPATION

Experiences of participation of the women in study V, were closely related to their understanding and to the respectful and personal encounters with the health care staff. The findings presented in themes and subthemes are illustrated as the voice of an imaginative patient in Figure 3.

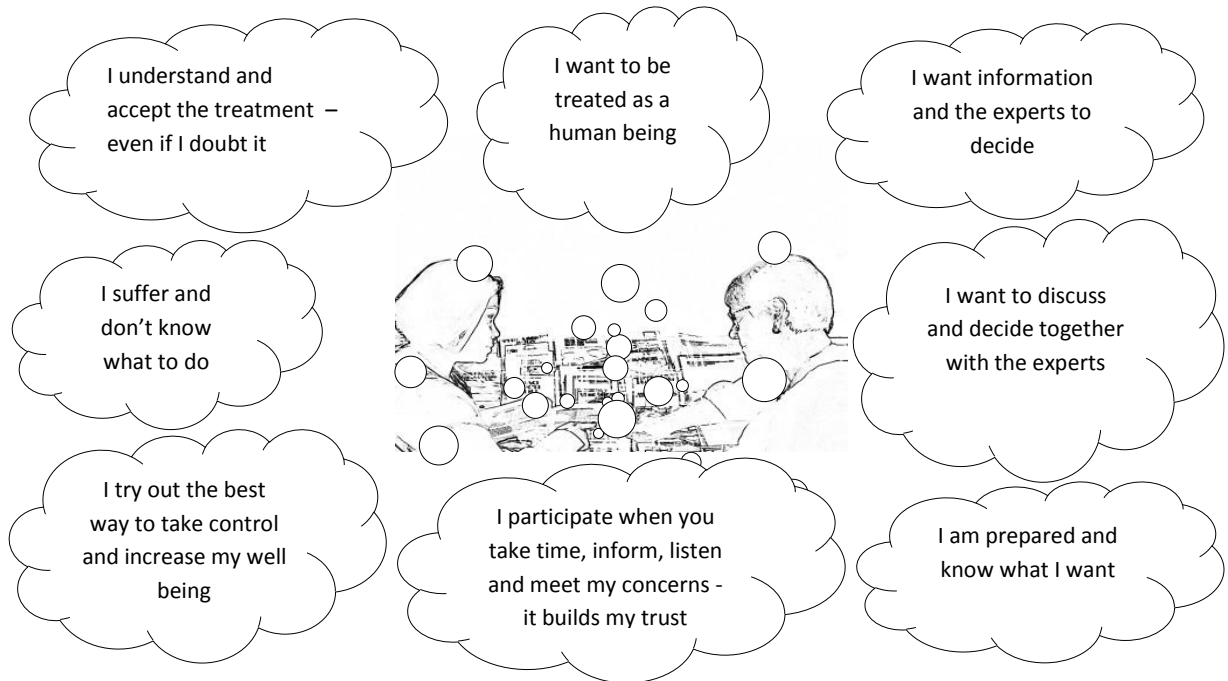


Figure 3. The themes and subthemes about patient participation in study V are illustrated by an imaginative patient voice.

All women have no choice but to participate in their breast cancer trajectory. They want to be part-owners to a varying degree, depending on their ability, understanding, situation, time and desire. One reason why some women wanted the experts to make the treatment decision for them was that they did not consider themselves knowledgeable enough. One could argue for supporting the women to learn more about the treatments to increase their possibilities to shared decision making. Considering the overwhelming situation of being diagnosed with breast cancer and the difficulties for the women to assimilate and process all the information, this might not be suitable or even possible to do. Nevertheless, the women were dependent on the understanding of the staff and its facilitating of their understanding. Even when the women in study V considered they were knowledgeable enough and expected to take an active part in the decision making they needed time to discuss available options and its' consequences with the staff. If the staff acknowledged this need of the women and took time to listen, answer questions and explain different alternatives, the women felt they were respected and taken seriously, which contributed to trust in the treatment and in the staff. Hence, the understanding of the patient is not the only factor to take into consideration regarding patient participation. Respectful treatment of the individual is the basis to develop trust in the care as found both in study III and V. The power imbalance between patients and staff needs to be acknowledged to facilitate patient participation (128).

The significance of the interaction between health care staff and patients to support their participation has been pointed out by others (83, 135, 139, 140, 184). Eldh (185) found that patients experienced participation when they felt confidence in themselves and in the staff, when they understood information, their bodies and procedures of the care and could

maintain control. When the patients did not understand, did not feel they were in control, lacked a relationship with the staff and felt they were not respected or treated as human beings, they experienced “non-participation”. These findings are in coherence with study V. Education of both staff and patients is therefore necessary, in order to accomplish participation of the patients, as knowledge and change of attitudes and roles of all agents are required (128, 135). Looking at the facilitating factors and the hurdles to participation found in study V might give us some ideas about the content of such an education. Learning about learning and how it can be supported could enhance the pedagogical competence of the staff. It could be beneficial for patients as well and therefore it is suggested to be part of future educations to all engaged in patient participation including the patients themselves.

The findings in study V, about the significance of respectful encounters, can add to theories about clinical encounters by pointing out the importance of acknowledging the patient as a person. A caring encounter in cancer care is described by patients, when the nurse is perceived as a caring and connecting companion who contributes to trust, well-being, health and empowerment (186). Friberg et al (148) compare the work above with their own observational and interview study in which they describe two different pedagogical encounters between nurses and patients: “Players in the same field pedagogical encounters” and “Players in different field pedagogical encounters”. The nurse in the “Players in the same field pedagogical encounters” invites the patient to a dialogue and uses different teaching strategies, including interpreting body expressions, to meet the patient’s need for understanding. The patients felt prepared and supported and the pedagogical encounter developed further. The nurse in the “Players in different field pedagogical encounters” did not support the patients when they sought knowledge from the nurse. The patients felt ignored and inferior. This led to feelings of worry and apprehension among the patients and to a breakdown of the pedagogical dialogue. The pedagogical encounter was found to prepare the patient for the future compared to the caring encounter which resulted in well-being in the present. Therefore health care organizations need to create a pedagogical climate with “same field pedagogical encounters”, as informal teaching is part of every-day practice in health care (148).

A “Same field pedagogical encounter” could be established by using a model presented by Silén (187) who builds on Uljens concept of pedagogical encounter. The model of a pedagogical encounter includes a learning situation. The agents involved can be students, teachers, patients, health care staff or others. There is a content to be learnt by using learning activities directed against a purpose and goal. All agents in a pedagogical encounter might learn from each other e.g. a patient learns from the experts in health care and the experts learn from the patient.

This has been illustrated by Stu Farber, a physician who became a patient when diagnosed with cancer and describes his meeting with the physician as an encounter between two worlds (188):

"My heart is full of good intentions.
I want to help using all I know.
I know a lot you don't know about
diagnosis, treatment, risks, benefits, statistics.
How can I assure you know enough
so you can make the right choices?
I protect my heart so I am safe
from making choices,
from sharing your life.

My heart is full of life.
I know a lot you don't know about
love, hope, grief, fear, illness, mortality.
How can I help you know enough about who I am
so you can help me make the right choices?
So we can share our knowledge and our lives?"

Stu Farber

The poem can be compared to the description of the objective and subjective concept of cancer described by Feigenberg (2). Barry et al (189) found four categories of communication between the patient and the doctor. In the category Strictly Medicine, both patient and doctor talked about physical complaints. In the category Mutual life world, patient and doctor talked about the patient's physical and psychological problems which made the patient feel recognized as human being. In the categories Life-world ignored and Life-world blocked, the patients were not recognized and had poor outcome in the communication (189). The authors conclude that using the voice of Mutual life-world would increase the outcome of the encounter and contribute to the treatment of the patient as a unique human being.

To increase patient participation in breast cancer care several measures are needed. An important part in the pedagogical encounter in cancer care is to treat patients personally, respectfully and establishing trust as demonstrated in the study above, in study III, IV and V and by others (148, 186). The demands on the patients to perform self-care have increased during the last decades as the time in hospital has been shortened. The findings in this thesis show that the contact nurse was appreciated. The needs of the patients, however, were not always met. The reasons were that the patients did not want to disturb the staff at the hospital, or that they did not understand what was happening in their bodies or if anyone could help. Considering the results in this thesis and the suggested "patient-as-partner" approach (137) additional resources for supporting patient learning and participation are needed, both in the short and in the long run. Rager (104) reported that women diagnosed with breast cancer perceived their self-directed learning as beneficial, but the problems were to find and evaluate information and support. In addition, negative emotions limited their ability to learn and use the resources. These women used self-directed learning, i.e. they initiated and searched resources without support from health care. Research on self-directed learning in education has shown that developing self-directedness requires a learning process of its own and guidance by a teacher (190). The role of the health care staff is therefore crucial in order to support patients to master their learning and find, evaluate, understand and use resources for learning.

6.5 METHODOLOGICAL CONSIDERATIONS

The studies in this thesis have focused on well-being, learning, understanding and participation of women in breast cancer care. Different research approaches were used to answer different questions.

6.5.1 Project I –Patients’ well-being (study I-III)

The methodology in project I was used to evaluate the effects of a shortened hospital stay after breast cancer surgery in combination with an increased continuity in the patient’s contact with the health care staff. In study I the short hospital stay was voluntarily chosen by the patients, which made it impossible to generalize the feasibility of an early discharge with a drain in place, to a wider population. It can be discussed if a randomized trial would have increased our understanding. Several factors need to be considered. At the time for study I, patients were treated at the hospital until the drain was removed. It was not considered possible, or even ethical, to force women to leave the hospital with a drain in place which they were expected to handle. Another factor is that randomized trials of early discharge demonstrated low participation and therefore general conclusions could not be made (163). The benefit of study I was that it was possible to compare well-being and characteristic among the women who preferred to leave the hospital early with drain in place with those who stayed until the drain was removed.

The main consideration about study II concerns the sampling. Many of the originally selected patients needed to be excluded, because they did not qualify as participants in one of the care models. There was also a discrepancy in the number of participants in the two groups. Hence, it was impossible to generalize the findings about the effect of the two care models, even if they were used as independent variables. The strength of using the regression analysis, on the other hand was that it revealed significant relationships between SOC and several variables measuring health and well-being, which are in accordance with others (37-43). The SOC-scale has recently also been found to be stable over time and a predictor of survival in women treated for breast cancer (164).

The questionnaire was developed for the study by one of the authors (HB) based on her clinical experience and research. An expert group of surgeons and registered nurses reviewed the questionnaire and supported the content validity. The content validity might have been strengthened had an empirical study of women’s perception of breast cancer been performed. As this was not possible, due to time constraint, an alternative solution could have been to co-create the questionnaire together with women treated for breast cancer to catch relevant questions from their perspectives. The study specific questionnaire was developed because no similar instruments were found at the time for project I. Today, it would have been suggested to use two of the most used questionnaires to assess quality of life in patients with breast cancer. The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Breast Cancer (EORTC QLQ-BR23) focuses on physical functioning. The Functional Assessment of Cancer Therapy-General (FACT-G) assess emotional well-being.

Both found to be reliable and valid (191). The instrument EORTC QLQ-INFO25 could be used to assess patients' perceptions of information regarding their cancer (90). A qualitative approach would have contributed to a more nuanced and varied picture and could have been included.

An open ended question, in the study specific questionnaire, was analyzed, as previous studies had shown that patients tends to evaluate their care more positively in closed than in open ended questions (192, 193). The analysis was inspired by Grounded Theory (154). The idea of Grounded Theory is that the research problem emerges from empirical data, which are analyzed through constant comparisons to create and refine theoretically relevant categories. The collection and analyses of data are done simultaneously. This was not possible to do in study III, as the data collection was already done when the analysis was performed. Instead the method was used as a guide for a stepwise analysis of the content of the answers to the open ended question. To avoid a distorted analysis, in favor of me as a contact nurse, a research colleague was involved in the analysis. Even if the amount of data was limited it revealed similar findings compared to others, discussed in study III. The categories of needs can also be related to the findings in study V.

6.5.2 Project II –Patients' learning and participation (study IV-V)

The participants in project II did not depend on me as a nurse. I informed the participants that I was not a member of the health care staff and that I did not have access to their medical records or any information, but the information they gave.

The strength of project II was that the qualitative approach gave rich data on the variation of learning, understanding and participation from the patients' perspectives. The recommended numbers of participants were in accordance with recommendations (151). The purposeful sampling (157) aimed for and fulfilled a great variation among the participants due to their demographic background and phases of treatment. However, the findings were limited due to the sampling. There were only a few women included, with other countries of origin than Sweden and therefore the cultural variation was limited. No women with advanced breast cancer were included and their learning and participation need attention in future studies. No men were included and therefore a gender perspective could not be obtained. Even if there are only a few men with breast cancer each year, it would be interesting to explore how their learning and participation is experienced.

The rich data was considered sufficient to answer our research question. However, the richness of data made it difficult to select meaning units, as most of the text was found to be useful in the analysis. Starting with a detailed analysis of a smaller portion of data, has been suggested in the abductive analysis (159). In accordance with the abductive analysis, seven interviews were selected for detailed analysis. This facilitated management of the data.

The coding and categorization of data were performed by one single person, myself. The collaborative analysis of data, conducted by me and my supervisor, contributed to deeper reflections and creative discussions. Triangulation, i.e. using multiple methods, empirical data

and perspectives, is considered to bring breadth and depth to an inquiry (150). Involving all members of the research team in the analysis, would have broadened the perspective, further. Including patients with other cancer diagnosis, e.g. men with prostate cancer, would also have contributed to a wider perspective and to more examples regarding patients' learning and participation. Other methods for collecting data, such as observation of clinical encounters and interviewing the health care staff, would also have increased our understanding of the phenomena.

7 CONCLUSION

The first perception of a breast cancer is often from the body, for instance, a lump in a breast, initiating a series of iterative interpretations, starting in preunderstanding, as well as with the expressed and concealed understanding of the patient. The purpose is to gain control and understanding of the new situation, to be able to take an active part in the treatment ahead, in order to achieve a state of well-being. This is, not least, a pedagogical problem. The present thesis has assessed patient well-being, but also described how the use of learning theories can contribute to improving the care of women with breast cancer. It has also demonstrated that the health care staff has an important pedagogical role to play in the care of breast cancer patients.

Patients must be recognized as unique individuals perceiving varying needs of care, learning and participation. Respectful and personal encounters, between the patients and the health care staff, are important prerequisites for learning and participation. The desire and ability to be a part-owner in decision making depends on the character of the decision, the situation, time and preunderstanding of the women. Participation is a possibility for the patients to influence decisions. Today it is imperative for patients to take responsibility for their own care, as the hospital stay is short. Vulnerability, lack of knowledge and complexity of decisions complicate patient participation. Access to health care and the understanding of the staff, are important in order for the patients to be able to participate. A new approach is therefore suggested which includes patients as partners and the staff as participants in the women's breast cancer trajectory. Both patients and health care staff would benefit from increasing their understanding about how they can become involved as partners in developing breast cancer care. The patients' understanding is essential for their participation. Therefore their learning needs to be supported.

In order to facilitate learning, information from all sources must be recognized. Special attention is needed to reveal concealed understanding, and how bodily sensations and events are interpreted. Time is essential to process information. Patients' understanding needs to be monitored and given feedback on repeatedly. The preunderstanding affects the interpretation of the current situation and needs to be explored, as do the interpretations of all sorts of information. The objectives for learning should be defined in dialogue with healthcare staff. That is, what do the women need to understand and what is relevant for them? Pedagogical competence in the interprofessional team is a prerequisite to facilitate patients' learning.

General theories of learning were found to be applicable to patient learning and the findings are considered to be transferable to patients with other cancer diagnoses. Compared to learning in general, the strong personal drivers of patients with cancer, are significant features. Learning, during a breast cancer trajectory, means that you need to understand and manage a life-threatening illness, both emotionally and cognitively. Vulnerability remains a challenge in developing understanding as cancer means uncertainty in relation to the disease, treatment, outcome, and one's own life.

7.1 IMPLICATIONS FOR FUTURE PRACTICE

The time constraints that prevail with short in hospital stays need to be addressed logistically in order to meet the needs of the patients both in the outpatient and in the hospital setting. Pedagogical competence is needed, in the interprofessional team in cancer care, to support patient learning. The model of pedagogical encounter could serve in this matter. Even the patients and relatives would benefit from “learning about learning”. This could support them in becoming partners in treatment and care. Legislation supports the enactment of patient education in other countries. According to the revised patient legislation in 2015 in Sweden the health care staff is obliged to follow up the patients’ understanding of the information received. The short clinical encounters in health care between health care staff and patients call for alternative solutions to support patients learning and participation. Additional resources are needed both within and outside the hospitals, for instance in primary care. The Learning and mastery centers in Norway can serve as good examples.

7.2 FUTURE RESEARCH

Much remains to be explored in patient learning. Future research is needed to increase our understanding about how to enhance patients’ possibility to become partners in their care. The findings in this thesis have been related to general learning theories and reveal significant factors needed to take into consideration, when implementing learning opportunities for patients and staff. Today comprehensive examples of learning opportunities, taking all these factors into account, are not known in Sweden. In order to explore and learn more about patients’ learning new innovative projects, based on current knowledge, need to be planned and implemented.

8 ACKNOWLEDGEMENTS

I wish to express my sincere gratitude to all who have supported me during the years and made the fulfillment of this endeavor possible.

First of all, I am deeply grateful to all women, who participated in the studies and shared their experiences during vulnerable periods in their lives.

Associate professor Charlotte Silén, my main supervisor and former head of the Centre for Medical Education. Without your engagement and firm support this work would never have been completed! Thank you for your guidance into qualitative research and for sharing your deep knowledge in the research field of medical education. It has been a true, creative learning experience! I am also grateful for your sincere interest in patient learning.

Professor Kerstin Sandelin and professor Yvonne Wengström, my co-supervisors, thank you for receiving me as a doctoral student and for re-introducing me to breast cancer care and research. Kerstin, thank you for prompt feedback and never failing support! Yvonne, thank you for sharing your great experience in breast cancer care and for all your good advices!

Professor Hjördis Björvell and associate professor Björn Cedermark, my previous supervisors. Thank you for introducing and guiding me into the scientific world in Project I. Nils-Olov Theve, Nils Wilking and Jan-Ulf Andersson for being my previous co-authors in Project I.

Professor Ann Langius-Eklöf, for invaluable support, for being my co-author, colleague and a dear friend! Your great knowledge and true engagement in research and education have been a continuous inspiration.

Professor Mats Brommels, and professor Carl Johan Sundberg, the previous and current heads of the department of Learning, informatics, management and ethics. I am ever so grateful for your support, making it possible to complete this thesis.

Roger Henriksson, Kjell Bergfeldt and Lena Sharp at the Regional Cancer Centre Stockholm Gotland, thank you for your invaluable support in making the studies about patient learning come true! A special thank you to Kjell who really understands the difference between receiving information and learning. Without your insight and enthusiasm for the project it would never have been realized!

Over the years a number of previous doctoral students, friends and colleagues have helped in many ways and I am grateful to: Lena Wettergren, Åsa Krusebrant, Catrin Björvell, Agneta Cronqvist, Kerstin Nilsson Kajermo, Birgitta Klang, Barbro Mendel, Bjöörn Fossum, Christina Forsberg, Ingrid Thorell Ekstrand, Anne Lindgren, Marie Louise Rosenqvist, Lena Karlsson and Britt-Marie Andersson.

To my former and present colleagues at the Unit for Medical Education, I wish to send my great appreciation! Especially I want to thank my competent and supportive roommate Ann-Kristin Sandberg and Maria Kvarnström, Lasse Uhlin, Juha Nieminen, Cormac McGrath, Linda Barman, Maria Weurlander, Klara Bolander Laksov, Ronny Sejersen, Therese Stenfors-Hayes, Anna Bonnevier, Klas Karlgren, Samuel Edelbring for all that I have learnt from and together with you. I am also grateful for all the help I have received from Elisabeth Lindgren.

Thank you Klara Bolander Laksov, for involving me in your research group about the clinical learning environment, together with Matilda Liljedahl and Erik Björck. It was a true collaborate learning!

Ester Mogensen, it has been a privilege to have known you for so many years as my colleague, friend and mentor! You taught me the importance of never stop being curious and the necessity of interprofessional learning!

I want to thank current and former doctoral students Carina Georg, Arash Hadadgar, Javad Jafari, Matilda Liljedahl, Per Palmgren, and Hanna Lachmann, for sharing their knowledge and for fruitful discussions.

I am deeply grateful for all the inspiring seminars and discussions with the members of the research group under the leadership of Charlotte Silén. Especially, I want to thank Janet Mattson, Charilaos Koufidis, Angelica Fredholm Nilsson, Nina Andersson-Papadogiannaki, Susanne Kalén and Katri Manninen for valuable feedback on my research.

The staff at the library at Karolinska Institutet have always provided excellent guidance when needed! A special thank you to Carl Gornitzki and Henrik Schmidt for helping me in desperate times!

I want to thank Susi and Thomas, for offering joyful and inspiring company, when I was struggling with my research! Anna and Peter thank you for the supporting messages from all over the world you're the best members of "The Association for preserving postcards"! A warm thank you to my singing friends, Majvor, Helena, Helene, Anna-Karin, Anne-Marie and Ingela for being there when I needed it most!

I am ever so grateful to my sister Marianne, who supports me in various ways with her sincere interest in the fundamental issues of life, including humor! Lars my brother in law, your never ending enthusiasm has always been a great inspiration for me! Johanna, my beloved niece, your curiosity, courage and endurance give me hope for the future!

My extended family: Nanna, Keith, Moa, Lasse, Ida, Sia, Odd, Tove, Viktor, Joel, Love, Emma, Frida, Tom, Julian, Anna, Milla, Laerke, Bosse, Juni - and Focus. You are all parts of the meaning of my life!

Without my life companion and best friend Stefan, this would never have happened! All our inspiring conversations, during long walks on the island with Focus, have been a wonderful learning experience for both of us. I will miss that! Thank you for all the good cooking, for managing our lives and for all the loving support. I cannot thank you enough! I am also grateful for your language revision, proof reading, and the cover picture!

This research was financially supported by the Swedish Red Cross College of Nursing and Health, the Swedish Foundation for Health Care Sciences and Allergy research, the Stockholm County Council, the Committee for the Health and Caring Sciences, the Research committee at the Karolinska Hospital, the Swedish Nurses Association, the Gunnar, Arvid, and Elisabeth Nilsson fund for Combatting Cancer, the Karolinska Institutet and the Regional Cancer Centre Stockholm-Gotland, Stockholm County Council.

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